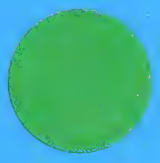
MANAGING AIDS SERVICES & RESOURCES



RA
643
.83
M36
1988

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service
Health Resources and Services Administration

The University of South Carolina
School of Public Health

DISCLAIMER

Throughout these presentations, opinions expressed, facts cited, and recommendations made, are the sole responsibility of the authors and do not necessarily reflect positions or policies of either the University of South Carolina, School of Public Health, or the Health Resources and Services Administration, U.S. Public Health Service.

The University of South Carolina is an Equal Educational Opportunity Institution and an Equal Opportunity/Affirmative Action Employer.

RA643.83
.M36
1988

MANAGING AIDS SERVICES & RESOURCES

Selected Readings
from a National Conference
August 1988

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service
Health Resources and Services Administration

•

The University of South Carolina
School of Public Health

INTRODUCTION

This volume contains readings from "Managing AIDS Services and Resources," a national conference held in Charleston, South Carolina, August 4-6, 1988. The purpose of the conference was to provide an opportunity for academic, public, and community health providers as well as community based organizations to gain new knowledge and information about current and emerging service delivery research and programs dealing with AIDS. The conference included sessions with featured speakers as well as a variety of workshops and presentations. Conference participants learned from experts in the planning of service delivery, from PWA's as service recipients, and from each other as service providers.

Editors:	Donna L. Richter, University of South Carolina School of Public Health Jon L. Nelson, HRSA, U.S. Public Health Service
Production and Layout Editor:	Sonja H. Snowdon, University of South Carolina School of Public Health
Copy Editors:	Dorothy Bailey and Blake Crawford, HRSA, U.S. Public Health Service
Editorlal Staff:	Susan Fulmer and Maxine Mixon, University of South Carolina, School of Public Health

TABLE OF CONTENTS

PAGE

Acknowledgements

Section I. Case Management and Treatment 1

AIDS Drug Assistance Program 3-5
Barbara L. McTague

Evolving Case Management Models in a Second Wave City 6-8
Andrew J. Kruzich

Case Management of Persons with AIDS: A Community Approach 9-11
M.A. Sevick, L. Klingensmith, S. Zucconi

Section II. Health Service Delivery Issues 13

Implications for AIDS Service Delivery in the Black Community 15-18
Donna L. Givens

Cost of Hospital Services by AIDS Patients From Diagnosis to Death 19-22
Stewart J. Landers, George R. Seage III, George A. Lamb, Arnold M. Epstein

Seattle-King County: A Model Program for Health Services Delivery 23-26
Patricia McInturff

Metropolitan Area HIV Services (MAHS) Project - A HRSA Funded AIDS Service Demonstration Project in Boston: A Progress Report 27-28
Martha W. Moon

Primary Care Issues 29-31
Anthony Scarsella

Developing HIV Specialty Services in an Academic Environment 32-34
Ronald O. Valdiserri

The C-100 Clinic: A Prototype for HIV-Related Primary Care In a Southern Public Hospital 35-40
Ted Wisniewski

Section III. Long-Term Care 41

A Long-Term Care Story: Fear is More Contagious Than AIDS 43-45
Kathryn S. Addenbrook, Alan W. Porterfield, James O. Bond

Home Health Care Services for People with AIDS: Enhanced Capacity Through Supplemental State Funding 46-49
Lisa Jeffery

Continuum of Care in Housing and Long-Term Care for Persons With AIDS: A Case Study 50-52
Andrew J. Kruzich

Managing Children with HIV Infection: The New Jersey Child Welfare Experience 53-55
Constance Ryan, Robert Hadfield, Terry Zealand, Faye Zealand

Section IV. Psychosocial Support Services for PWAs 57

Multi-Family Support Group for Transfusion Related HIV-Positive Recipients 59-61
Susanne Wise Campbell

AIDS and Volunteers 62-65
Virginia D. Crosby

A Three-Session Psychoeducational Group for HIV-Seropositive Individuals 66-70
Michael Gross, Robert Carr, Shelley Bruaer, Abe Feingold, Patricia Giulino, Lee Ellenberg, Allan Tweedy

The Psychosocial Effects of Early HIV Identification 71-74
Kenneth Hoffman, Jeanie Onitsuka, Tim Clark

A Model of Psychosocial Intervention in a Family Pratice Center: For Persons With Human Immunodeficiency Virus 75-78
Joyce Perkins, T.J. Woolridge, R.A. Francis

Section V. AIDS Challenges for Health Care Workers 79

AIDS and the Hospital Health Care Worker 81-86
Judith Cooksey, Joan Dworkin, Gary Albrecht

AIDS Patients and Social Workers: The Relationship Between Burnout, Physical Symptomology and Potency 87-91
Marcie Egan

AIDS and Dentistry: What Does the Public Think? 92-96
Barbara Gerbert, Bryan Maguire, Sherry Spitzer

Stress and Burnout in the AIDS Health Care Worker 97-101
Donna L. Higgins, Deborah Rugg

Section VI. AIDS Education for Health Professionals 103

Teaching AIDS in Medical School: Curricular Issues and Strategies 105-110
Francois E. Alouf

The East Central AIDS Education and Training Center for Health Care Professionals 111-113
Lawrence L. Gabel

Health Professionals and AIDS: The Need to Know 114-116
Nancy Kilpatrick, June Horner

Preparing Community Dentists to Provide Care to HIV-Positive Patients: An Educational Needs Assessment 117-122
Bryan Maguire, Barbara Gerbert

AIDS Education for Health Care Professionals 123-125
Erline P. McGriff, Patricia M. Hurley

Oregon State Health Division HIV Program: Train the Trainers 126-128
Paula Radloff

AIDS in Medical Education 129-131
Lee Strunin, Arthur Culbert, Stephen Crane

Section VII. Mobilizing Community Resources 133

Training Volunteers at Vanderbilt AIDS Project 135-137
Ruth A. Sheets, A. Gene Copello

A Street Outreach Worker Consortium for AIDS Education 138-140
Sylvia Silver, Billy S. Jones, Aaron Green, Beck Young

A Program of the Vanderbilt AIDS Project: Developing AIDS Programs In Rural Tennessee 141-143
M.D. Roberts, A. Gene Copello

Section VIII. Sharing AIDS Information 145

Women and AIDS in New York: An Organized Community Response 147-149
Marilyn Iris Auerbach, Claire Jagemann, Joanne Mantell

National AIDS Information Clearinghouse 150-151
Ruthann Bates

Media Use Among Gay Men in Dallas 152-157
Marc Lerro, Anne C. Freeman, C.E. Haley, J. Tabori

A Model State Legislation: The Washington State AIDS Omnibus Bill 158-160
P. McInturff, A. Kruzich, B. Kelleigh

Section IX. Health System Response to PWA Needs 161

Thoughts for Health Care Providers Responding to PWA Needs 163-165
Steve Beck

The Health System's Response to PWA Needs: Existing Problems and Suggested Improvements 166-171
Don Schmidt

A Personal Experience of the Health Systems' Response to PWA Needs 172-176
Andrew M. Ziegler

ACKNOWLEDGEMENTS

Many individuals contributed many hours of hard work to plan and conduct the conference on Managing AIDS Services and Resources and to produce this volume of readings. The conference has been most helpful to health professionals in providing optimal care to people living with AIDS, ARC, and HIV infection. We thank the participants and staff who made this project possible. We are also grateful to the concluding panel -- people living with AIDS and HIV infection -- who gave an eloquent, and to some an unsettling, perspective on their health care needs. The conference owes a special note of appreciation to the Planning Committee, whose work contributed substantially to its success.

Planning Committee

Samuel C. Matheny, M.D., M.P.H., Associate Administrator for AIDS, HRSA, USPHS

Charles L. Hostetter, M.D., Director, Office of Special Projects, BMCHRD, HRSA, USPHS

Paul Kawata, Executive Director, National AIDS Network

Jane Silver, Chief, Office of AIDS Activities, D.C. Health Department

Elmer Smith, Director, Office of Eligibility Policy, HCFA

Jon L. Nelson
Conference Director
Office of Special Projects
Bureau of Maternal and Child Health
and Resources Development
Health Resources and Services
Administration
United States Public Health Service

Donna L. Richter, Ed.D.
Conference Director
Assistant Dean
School of Public Health
University of South Carolina
Columbia, S.C.

Case Management and Treatment

AIDS DRUG ASSISTANCE PROGRAM

Barbara L. McTague, Director, AIDS Drug Assistance Program, New York State Department of Health

As part of the Fiscal Year 1987 supplemental Federal appropriation, Congress provided an appropriation of $30 million for the Public Health Emergency Fund to help States cover the cost of zidovudine (azidothymidine, AZT) and other drugs determined by the Food and Drug Administration (FDA) to prolong life in people with AIDS (PWAs). The grant, which is administered by the Health Resources and Services Administration, was provided to pay for the costs of AZT for individuals not covered under the State Medicaid program or other third-party payors.

New York State received an $8.5 million grant which is effective August 10, 1987 through September 30, 1988. The New York State Department of Health, through its AIDS Institute, established the AIDS Drug Assistance Program (ADAP) for the purpose of administering the grant. ADAP, which was implemented on September 15, 1987, provides AZT to medically and financially eligible individuals. Over 1,300 applications for ADAP assistance have been received, and over 1,000 people with HIV infection have already been made eligible, with 41 percent minority enrollment.

ADAP determines client and provider eligibility, issues program eligibility cards, pays claims to over 450 community and hospital pharmacies participating in the program and reimburses the ADAP designated wholesaler. Through a competitive bidding process, the program has achieved pricing for AZT that is 16 percent below the average wholesale price.

A process has been established to provide temporary assistance to persons eligible for, but not yet receiving, Medicaid. Interim coverage is provided until Medicaid benefits become available. It is expected that this provision will help ensure intravenous drug users have access to AIDS drugs, since that population has difficulty maintaining eligibility status in the traditional assistance programs. Assistance is provided to individuals with inadequate third-party insurance coverage. Procedures have also been established in conjunction with the New York State Divisions of Parole and Corrections to ensure parolees from State correctional facilities continue to have access to drug treatment when they enter into the community.

New York State has the largest and most diverse AIDS population. ADAP has an extensive outreach program to ensure all categories of infected individuals, including minorities, intravenous drug users, homosexuals, women, prisoners, etc., have access to drug treatment.

A committee of expert clinicians and researchers has been convened to recommend medical protocol for drug treatment and to review other drug

treatment issues including drug use in the pediatric environment, and inclusion of new drug therapies into the program. ADAP clinical staff, in conjunction with the advisory committee, have begun to supply much needed information on AIDS drug-related issues as they pertain to New York State.

The need for a program providing assistance with drug costs in New York State will continue. Individuals who are HIV positive will become symptomatic in increasing numbers. In the absence of a vaccine or a cure, increased emphasis will be placed on the need for drug treatment. Many individuals are employed in jobs that provide little or no health insurance coverage. Many of those individuals with inadequate health insurance coverage are those most at risk for HIV infection. The fiscal implications of information conveyed at Stockholm regarding the trend towards early, aggressive chemoprophylaxis is of great concern to New York, since there is a large number of asymptomatic HIV infected individuals residing in the State, many of whom may need financial assistance to obtain drug treatment.

In addition to concerns about financial access, the majority of HIV infected individuals in New York State do not have adequate access to drug treatment under the present national drug trial and approval system. While improvements in the clinical trial/approval process are occurring, problems restricting access to drug treatment continue to exist. One year after the clinical trials program was implemented, actual patient enrollment was less than one-half the targeted number. Although the situation has improved, only 2,853 patients were enrolled in all studies by February 1988. New York State has more than 25 percent of the Nation's AIDS cases; however, as of March 1988, approximately 17 percent (497) of the clinical trial participants were from this State.

Minorities are underrepresented in all clinical trials. This inequity is particularly evident in New York State where Blacks and Hispanics represent 57 percent of the AIDS cases in the State, but only 26.5 percent of the participants in clinical trials (as of March 1988). IVDUs, who represent an increasing percentage (currently 36 percent) of the AIDS cases in the State, are also excluded from the trials. HIV-infected prisoners, many of whom are minorities and/or IVDUs, have also had limited access to treatment protocols. Exclusion of minorities and IVDUs from access to drug treatment and drug trials often occurs because of the special recruitment and support requirements for a population alienated from mainstream medical care, the lack of research units in areas where minorities and IVDUs reside, and the presumption that they would be non-compliant and would potentially have adverse drug reactions.

Development of therapeutic drug trials for children with AIDS has lagged significantly behind development for the adult population. Some adults, women in general and pregnant women particularly, have also had limited access to drug trials. Although 31 percent of children with AIDS reside in New York State, State institutions have been relatively excluded from the development of pediatric clinical trials. Most children with AIDS are from poor, minority families, where one or both parents are IVDUs. As a result of the lag in the pediatric

clinical trials, many of these children have been denied access to potentially life-prolonging drug treatment.

Clinical trial development and implementation traditionally have been within the purview of academic/tertiary institutions. Because of the lack of involvement of community hospitals and health care centers, community-based organizations, and local practitioners in the clinical trials system, a valuable resource for increasing the accessibility, availability, and acceptability of clinical trial protocols, especially for underserved populations such as minorities, has been by-passed.

New York State plans to increase the availability of information regarding HIV-related drug treatment and clinical trials by creating an AIDS drug information center. The center will not duplicate existing resources, for example the American Foundation for AIDS Research (AmFAR), and will be tailored towards New York State problems and experience.

Center staff will respond to inquiries from patients, physicians, and organizations regarding drug treatment and clinical trials in New York State. The center will publish a quarterly newsletter that focuses upon access to drug treatment and clinical trials in the State. An anonymous registry profiling individuals in the State who are participating in drug trials will be established and analyzed to identify underserved populations. A broadly based advisory committee will be established to make recommendations regarding access to drug treatment. A survey of the clinical trials network in New York State will be performed. Finally, an implementation plan will be prepared for a pilot project to develop a limited number of community-based trials in high seroprevalence and underserved areas.

By combining the operational activities of ADAP and the information resource center, New York State hopes to have an effective approach which will ensure all its HIV-infected individuals have appropriate access to drug treatment.

EVOLVING CASE MANAGEMENT MODELS IN A SECOND WAVE CITY

Andrew J. Kruzich, Project Coordinator, Seattle-King County AIDS Health Services Program

Case management was one of the first publicly funded social services for persons with AIDS in Seattle-king County. The need for case management was prominent in the February 1986 report of the Mayor's AIDS Task Force, which set the course for development of AIDS services in Seattle-King County. That report suggested that case management could resolve the issues of:

- fragmentation of services and programs
- service gaps
- duplication of services
- programs working at cross purposes
- incomplete service arrangement and delivery
- slow response to special needs of PWAs

In 1986, the City of Seattle funded AIDS case management at the Northwest AIDS Foundation (NWAF) at a level of $40,000.

The Mayor's AIDS Task Force Report also recommended that the Seattle-King County Department of Public Health be designated the lead agency for AIDS programs. Thus, planning for the development and funding of AIDS service programs, including case management, is the responsibility of the Health Department. In planning case management services, three models were reviewed:

- Senior service programs (social service model)
- Health Maintenance Organizations (medical model)
- Insurance companies (cost control model)

Primarily because of the urgency in connecting persons with AIDS to social and health care assistance programs, the social service model was selected as highest priority for development. It is recognized, however, that as the overall costs of AIDS care increases, the other two models, and particularly the cost control model, will become increasingly important.

Four types of activity are required in current case management contracts in the Seattle-King County Program:

- screening
- referral
- comprehensive assessment of need
- detailed individual service plans

These four activities are further broken into two types of functions: core functions and support functions. Core functions include intake evaluation, the service plan, plan implementation and periodic service plan review. Support functions include individual client advocacy, direct assistance in obtaining services, consultation with other client service providers, networking with the client's support system, and family support.

Because of limited resources, priorities must be established for the client population to be served. The highest priority is for persons with AIDS and severe AIDS-related conditions who have multiple health and social service needs, are unable to obtain assistance on their own, and have no family and friends to help.

In addition to the above types of activities, case managers are also involved in the Robert Wood Johnson Foundation (RWJ) data collection system, and are requested to participate in community needs assessments and program development activities.

In 1988, the Seattle-King County AIDS Health Services Program has approximately $314,000 committed to AIDS case management services, including $51,000 from the Robert Wood Johnson Foundation, $63,000 from the Health Resources and Services Administration (HRSA), $80,000 from the city of Seattle, $35,000 from King County, and $85,000 through a Title XIX AIDS case management contract with the State of Washington.

The Seattle-King County Department of Public Health receives these funds and subcontracts for services in the community. There are currently two sub-contracts with the Northwest AIDS Foundation, the major community-based AIDS agency, and Harborview Medical Center, a County-owned public hospital. A contract is also currently under negotiation with Group Health Cooperative, the major HMO in the State.

The RWJ Management Information System (MIS) was started in October 1987, in Seattle-King County, and 6 months of data reveals that the population served through the case management system closely parallels the characteristics of all persons diagnosed with AIDS in the County in terms of sex, age, race, and method of transmission. In mid-1987, the AIDS Health Services Program conducted a survey among all PWAs and their physicians in the County, which reviewed their level of assistance needs. Comparisons of that data with the MIS indicates close parallels in terms of employment status, insurance coverage, living arrangements, and level of assistance needed. An RWJ client survey evaluation which will commence this fall will be of further assistance in determining if the program is reaching a cross representation of persons with AIDS in the community and adequately addressing their needs.

The Seattle-King County AIDS Health Services Program is attempting to maintain a relatively centralized and coordinated case management system that is also accessible to clients in a variety of settings. With RWJ funds, the Program is currently preparing a five-year plan for case management services

which will address many issues such as centralization versus of decentralization as the need for services grows. Because the Health Department is the lead agency, and funding from grants and other sources is concentrated, there is an ability to ensure that case management services are relatively consistent and an ability to change the service definition, if necessary, to reflect changing client needs.

The Northwest AIDS Foundation will continue to play a lead role in provision of case management services. The growth rate in case management staffing at that agency from one in 1986 to 4.5 in 1987, and the addition to their program of an Information and Referral Service and a volunteer case management assistants component indicates the flexibility with which a community-based agency can respond to increasing needs.

The biggest challenge to the Seattle-King County Program is demonstrated by reviewing a projected caseload over the next 5 years. While funding of current case management services provides for a reasonable caseload of 30-35 clients at Northwest AIDS Foundation and 45-50 at Harborview, those caseloads projected into 1991 and 1992 would require financial and management resources that are unattainable. Thus, it will be necessary to increase caseloads or further restrict the client population served. Assuming that medical therapies will also become more effective over this period, and result in a higher number of persons living with AIDS in the community, there is a danger of the system becoming overwhelmed. One solution that will be examined is a computerized system somewhat like the HRSA-funded effort currently underway in Los Angeles.

Another major challenge will be the inevitable pressure to incorporate the cost control model discussed earlier into the existing social service model. Significant resources will need to be made available to plan and develop a system that can serve both purposes effectively.

CASE MANAGEMENT OF PERSONS WITH AIDS: A COMMUNITY APPROACH

M.A. Sevick, Allegheny Conference on Community Development; L. Klingensmith, University of Pittsburgh; S. Zucconi, University of Pittsburgh

The Case Management Project described below is a project of the Pittsburgh Program for Affordable Health Care (PPAHC). PPAHC is a community-based program devoted to (i) curbing the rising costs of health care, and (ii) protecting the quality of and access to care. It was created under the leadership of the Allegheny Conference on Community Development, and funded by the Robert Wood Johnson Foundation. Initial planning for the program was coordinated through the Health Policy Institute at the University of Pittsburgh. PPAHS is sponsored by ten local business, health, and labor organizations.

Within its primary goal of cost containment, PPAHC is working to limit the use of expensive acute care facilities and to maximize the availability and effectiveness of alternative community services for non-acute and long-term care. Toward this end, three separate but complementary projects have emerged. The Community Health Care Utilization Management Program (CHUP) has developed model clinical criteria and administrative guidelines for utilization management. The Case Management Project is involved in the development, implementation, and evaluation of model processes, standards, and guidelines for case management and discharge planning. This project, in particular its applicability for AIDS service delivery systems, is discussed in more detail below. The Service Inventory Project is developing a computerized inventory of all health and social services in the Pittsburgh area. It will be available to health care and other providers in Allegheny County on a subscription basis.

Case Management Model Development. Due to recent policy initiatives to contain costs as well as changes in the needs of consumers of health care, this country is witnessing a renewed interest in community-based care. Case management, a mechanism for coordinating community-based services for clients, is a term that has recently gained tremendous popularity. It has been identified by a number of government agencies, service providers, and foundations as an effective way to deal with the needs of certain client groups, including persons with AIDS (PWAs). This has occurred, however, without any consensus regarding the definition, purpose, processes, or standards of providing case management services.

PPAH's Case Management Project is a local community effort to define case management, the processes used, and basic minimum standards surrounding case management activities. The model is the product of 15 working committees drawn from the Pittsburgh health care community. A variety of disciplines and clinical interest areas are represented on these committees, as

well as the different types of organizations involved in coordinating community-based care (i.e. home health, hospital, social service agencies, and utilization management companies).

The model contains some very general content including: (i) a definition of case management, (ii) an outline of the essential components of the process, (iii) a case manager job description, and (iv) administrative guidelines for operating a case management service. The principal content of the model, however, is contained in two sections - the "generic model", and a section containing a series of "diagnosis specific scenarios". The generic portion of the model takes each step of the case management process and breaks it down into a specific set of activities, standards that apply to these activities, and suggested guidelines and instruments that can be used in performing the various tasks associated with coordinating services for the client. This section of the model is referred to as generic, in that the processes, standards, and guidelines are purposefully broad. They are felt to be the basic minimum activities for effective case management, applicable for any type of agency and any type of client. The diagnosis-specific scenarios illustrate application of the generic standards to clients with specific problems. Scenarios identify the common problems experienced by the client, goals that should drive the service plan, service needs related to each problem, and providers that can be utilized in meeting service needs. In addition to a scenario for persons with AIDS, others have been developed that address problems of the elderly, psychiatric clients, and individuals requiring physical medicine/rehabilitation.

Model Validation. The model was developed by area professionals, using a consensus building process. The next order of business has been to determine how the model would fare under the constraints of a "real" service system. To determine the utility of the model for the community, the current practice patterns of 20 case management agencies are being compared and contrasted to the PPAHC model. Data is being gathered via key informant and focus group interviews. Discrepancies between the model and practice are being examined to determine whether they are due to inadequacies of the model (i.e. standards are not appropriate for certain target groups) or due to system barriers (i.e. inadequate reimbursement, lack of community services, placement problems, etc.). Information on model inadequacies will be used to amend the model. Information regarding barriers to implementation of the model will be used to formulate policy statements regarding the system of community-based care. It will enable the authors to define exactly what is going on in the community with respect to case management, where gaps in services exist, and how linkages between agencies can be improved.

In planning for the development of health care services, community or market assessments must be done. The important components of doing such an assessment are: (i) identifying the population at risk, (ii) defining their service needs, and (iii) defining the health resources available to meet their needs. Using the PPAHC Case Management Model as the standard for comparison, health resources and the adequacy of the service system are being defined. This effort is being complemented by a study sponsored by the Health Policy

Institute at the University of Pittsburgh. The specific aims of this study are to develop a surveillance methodology, characterize and project health care utilization patterns and resource needs, and compare resource availability with projected needs for AIDS and ARC patients in Southwestern Pennsylvania. These two studies, combined, will clearly define the health care resource needs of PWAs in the region, and will provide a foundation for policy recommendations regarding the development of services and reimbursement for care.

Health Service Delivery Issues

IMPLICATIONS FOR AIDS SERVICE DELIVERY IN THE BLACK COMMUNITY

Donna L. Givens, Community Health Awareness Group, Detroit

I. Background

A. Prevalence of AIDS in Michigan's Black community

- Blacks comprise 45% of all statewide AIDS cases
- Blacks comprise 13% of the Michigan population
- 45% of all AIDS cases occur in Detroit
- Between June 1987 and May 1988 the proportion of Blacks with AIDS increased from 45% to 49% of the total

B. Prevalence of AIDS in Michigan vs. high impact States

- 689 cases in Michigan
- 16,337 cases of AIDS in New York
- 13,735 cases of AIDS in California
- 4,744 cases of AIDS in Florida
- Michigan ranks 19th in total number of AIDS cases

C. Implications of low AIDS prevalence

- Opportunity for pro-active policy
- AIDS will be felt most strongly within Black community
- Cycle of poor health care, risky behavior, and disease in Black community
- Raj Weiner: "distressingly wide and, in some cases, growing gap in health status between minority Black and majority population in Michigan."
- Geometric progression in number of AIDS cases
- Need for timely, coordinated, appropriate response

D. Assessing the risk in Detroit's Black community

- IVDU rate in Detroit second only to New York City
- Between 32,000 and 50,000 IVDUs in Detroit
- Decline in number of treatment slots/methadone clinics
- sizeable number of black gays in Detroit
- Gonorrhea and syphilis transmission rate in Black community reported as 11 times greater than in White community in Michigan
- Crack houses potential source of HIV spread

E. Structural Disparities in Health Services to Blacks

- two models for health education

1. Community Model - Clair Turner
   Community advocacy/community education
2. Professional Model - Paul Mico and Helen Ross -
   Behavioral science/health behavior

- Professional model predominates thereby alienating Blacks
- Ohio Task Force on Black and Minority Health: "most health services today are planned, designed, and implemented in a manner which excludes the values, beliefs, and attitudes of the minority community."

F. A Community Health Awareness Group (C-HAG) 1985

- Based on community model
- AIDS education for Blacks
- Linda Williams: "cooperative action between community-at-large and population groups at risk for AIDS."
- Up to that point, AIDS education services non-existent for Blacks.
- Wellness Networks - AIDS services to White gays since 1983

II. C-HAG 1988

A. Agency Description

- Centrally located in Black community
- Street outreach, outreach at treatment sites, HIV antibody counseling and testing, crisis intervention, support group, community resource referral
- Indigenous staff - entirely Black, high risk backgrounds
- transition from voluntaristic to full service agency

B. C-HAGs legitimacy as AIDS service provider

1. Client population

- "hard to reach" clients
- Black gays "closeted"
- intravenous drug use - illegal
- widespread poverty, alienation from health care system, chemical dependency - IVDUs and Black gays
- IVDUs - stereotyped as suicidal, criminal, uneducable

2. C-HAGs clientele

- C-HAG staff have informal access to networks of high risk Blacks
- informal access developed into formal mechanism for reaching clients
- 40% of Blacks with AIDS in Detroit are IVDUs; 40% are homosexual/bisexual
- 18% of C-HAGs counseling and testing clientele are IVDUs and 18% are homosexual/bisexual
- 34% of C-HAGs positive clients are IVDU and 37% of C-HAGs positive clients are homosexual/bisexual
- 391 clients between October 1987 and July 1988
- 10.4% seropositivity rate; 20% among gays and 21% among IVDUs

3. Questions of legitimacy

- indigenous workers not recognized by professionals as legitimate source of health education services
-Linda Williams: "The expertise of a community representative is a status conferred by his/her peers - not the professional"
- C-HAG known as IVDU agency despite services to Black gays
- C-HAG advocates for IVDUs/unpopular positions despite similarity to widely accepted positions taken by gay advocacy groups
- C-HAG viewed as gadfly agency

4. Linkages with Detroit Health Department (DHD)

- subcontractual relationship - DHD provides technical support and administers MDPH
- Shared philosophy toward client
- DHD advocates for the "IVDU" agency: C-HAG
- C-HAG representatives sit on DHDs IVDA AIDS Task Force and Women and AIDS Committee
- with DHDs support C-HAG representatives gained reluctant access to the Governor's Task Force on AIDS, Michigan Media AIDS Task Force, and Maternal and Infant AIDS Task Force

5. Linkages with other health care providers

- University Health Center - HIV Clinic
- Substance abuse treatment centers
- Detroit Receiving Hospital - stepdown unit; New Center Hospital - stepdown unit

C. Creating Service Demands

1. outreach created demand for counseling and testing
2. counseling and testing generated demand for post-diagnostic services

    - support group
    - post-diagnostic education
    - resource referrals
    - treatment referrals

3. C-HAG clients are generally poor, chemically dependent, not receiving public assistance
4. Clients recruited by counseling and testing services need appropriate medical referrals
5. Post-diagnostic services create a demand for "buddy" services and increased provision of resources

    - chore services
    - hospital visitation
    - emergency funds

6. C-HAG staff attempt to close the gap in services by providing a mix of paid and volunteer hours.
7. Post-diagnostic services are not a funding priority

    - IVDUs seen as critical link between high risk and general populations. Services are meant to prevent this worst case scenario
    - post-diagnostic services are not seen as part of prevention
    - few expendable resources within Black community

III. Community Health Education is a Vital Component of AIDS Risk Reduction Within Minority Communities

- Indigenous workers serve as credible sources of information
- Indigenous groups are able to access hard-to-reach populations
- It helps to maintain a continued commitment to health promotion
- Services must be coordinated with those of local health department and other local service providers

COST OF HOSPITAL SERVICES BY AIDS PATIENTS FROM DIAGNOSIS TO DEATH

Stewart J. Landers, Boston Department of Health and Hospitals, Massachusetts Department of Public Health;
George R. Seage III and George A. Lamb, Boston Department of Health and Hospitals and Boston University School of Public Health;
Arnold M. Epstein, Department of Medicine (Division in General Medicine, Program in Health Services Research), Brigham and Women's Hospital, and Department of Health Care Policy, Harvard Medical School, and the Department of Health Policy and Management, Harvard School of Public Health.

The Massachusetts Cost of AIDS Study, began in 1984 with support from the Massachusetts Department of Public Health and the Boston Department of Health and Hospitals, has studied inpatient and ambulatory hospital costs, and ambulatory health center costs for AIDS and ARC patients.

The first study, a 1 year look at 45 AIDS patients at one Boston teaching hospital, estimated the cost of AIDS to be $46,505 per year of $50,380 over a projected time from diagnosis to death of 13 months (1). This figure included both inpatient and hospital based outpatient costs. All persons with AIDS receiving primary care at this hospital between March 1, 1984 and February 28, 1985 who met CDC criteria for AIDS were included. Patients who did not receive their primary care (as opposed to a consult visit) at the institution were excluded. Sociodemographic data and clinical characteristics were obtained by reviewing ambulatory and inpatient hospital records. Outpatient and inpatient services were evaluated by reviewing medical and billing records. Hospital charges were converted to costs by applying Massachusetts Rate Setting Commission charge/cost ratios. A coded list of names and dates of birth was compared with Massachusetts surveillance data to validate completeness of cases reported by the hospital, to verify dates of diagnosis and to update dates of death. The methodology has remained essentially the same for subsequent phases of the study.

The first sample of 45 patients was small, represented only one caregiving institution, and was demographically homogenous - 98 percent male, 93 percent gay or bisexual. To improve the representativeness of the sample we expanded the study to include five hospitals, one of which is a public hospital, and one of which is from the western part of the State. This cohort of 240 people with AIDS was somewhat more representative, although it was still disproportionately male (93 percent) and gay or bisexual (81 percent) compared with the overall Massachusetts caseload. In comparing costs at each of the five hospitals over a two-year period there was a decrease in cost at each site from the first to the second year. This decrease in cost was attributable to a decrease in the mean number of hospitalizations per year (from 2.2 per patient

to 1.9 per patient) and a decrease in the mean length of stay (from 19.2 days per admission to 15.7 days per admission) (2). Possible explanations for these decreases include the increasing familiarity with AIDS and its various manifestations, the standardization of treatments, and improved home care, support services and discharge planning. None of these explanations have been proven to decrease cost or utilization of services for patients with AIDS.

Further analysis of these cost decreases raised questions as to whether we were seeing a true reduction in cost or an effect of the growing epidemic on our cohort. This "epidemic effect" is created by the lack of information about the relationship between cost and stage of illness for AIDS patients. Our data indicated that terminal hospitalizations tended to be very expensive. If, however, the early stages of AIDS tended to be very inexpensive, the decrease in cost may have been due to an epidemic effect. Thus, if more newly diagnosed cases entered our study in the second year and if all of those patients had low costs, the second year would present a lower average cost per patient.

In response to concern about this "epidemic effect", all data was recoded, with outpatient costs assigned to the month they occurred and inpatient costs assigned to the month of hospital admission. Cost and utilization was then analyzed based on a cost per month basis, thus allowing costs to be analyzed with respect to time from diagnosis (3).

The incidence of hospitalization was found to be highest at the time of and immediately following diagnosis. (Incidence of hospitalization is high at two times - at diagnosis and at death. However, if time is measured starting at diagnosis, the greatest probability of hospitalization will occur at that time. A temporal association with terminal hospitalizations will be less noticeable since individuals die at various times subsequent to diagnosis.)

To determine variables associated with long lengths of stay and subsequent high utilization, a general linear model (GLM) Least Square Means program was used to derive cost figures while controlling for differences in race, gender, transmission category, institution, age, primary diagnosis, insurance and mortality status, chronological time, and stage of illness. Patient months without inpatient utilization were deleted so as to analyze the intensity (rather than frequency) of hospital utilization subsequent to diagnosis. The results show hospitalization costs do not change significantly with respect to time subsequent to diagnosis (3).

An additional 2 years of data has been collected on surviving members of the cohort. Data collection and processing is currently complete on inpatient utilization at three institutions, two private teaching hospitals and one public hospital in the city of Boston. These sites include data on 128 of the original 240 (53 percent) people with AIDS. Because data is not yet available from two hospitals, the demographics of this sub-group differs from the original cohort. Of these study subjects, 63 percent are white, 90 percent are male, and 73 percent are gay or bisexual. Insurance coverage of the cohort is as follows: 57 percent

are insured privately, 24 percent are insured by medicaid or medicare, and 19 percent had no insurance.

Patients for whom a death was recorded before the end of the four-year period (n=88) were labeled "deceased" patients, and the remainder (n=40) were labeled "live" patients. The demographics of the live and deceased patients are similar. Some differences were noted. First, more deceased patients (n=56, 64 percent) presented initially with Pneumacystis carinii pneumonia (PCP) as compared with live patients (n=18, 45 percent). Second, more live patients were found to have no insurance (n=11, 28 percent) than deceased patients (n=13, 15 percent). Third, more live patients (n=16, 40 percent) were seen at the public hospital than deceased patients (n=12, 14 percent). Lastly, more deceased patients were gay (n=68, 77 percent) than live patients (n=26, 65 percent). The last three findings run counter to the usual assumption that uninsured patients seen at public hospitals are likely to have shorter survival times than gay (and presumably more affluent) men. These findings may be related to a high incidence of PCP among gay men. Another explanation may be related to a limited ability to follow-up on the care of patients from a lower socio-economic class. A more extensive follow-up on live patients is planned to determine whether accuracy of mortality reporting may play a part in these results.

For 88 deceased patients the average cost of inpatient care was $30,283 with 2.9 hospitalizations and an average of 49 hospital days over 9.8 months. For 40 live patients, the mean cost of inpatient care was $22,545 with 2.6 hospitalizations and an average of 35 hospital days over 11 months ($p<.05$ for comparison of hospital days between deceased and live patients). Information on AZT utilization by this cohort is not available, however, and it may be one factor accounting for the difference in cost and hospital days between the two groups.

Among the deceased patients for whom we have inpatient utilization from diagnosis to death (n=88), cost and hospital days varied according to race. The cost and number of hospital days for deceased non-whites (n=30) were $39,394 and 62.4 days, which are both significantly higher than that of deceased whites (n=58), $25,571 and 42.4 days ($p<.01$). Also, the number of months from diagnosis to death for gay or bisexual men (n=68) was 10.7, compared to 6.7 for all other transmission categories combined (n=20) ($p<.05$).

This is a preliminary analysis of 4 years of utilization data on a cohort of persons with AIDS. Further data collection and analysis are needed to understand the implications of this information. It suggests, however, that Massachusetts and other localities need to look further at various health care delivery systems in order to better understand health services utilization by persons with AIDS. Access to care needs to be studied to evaluate the relationship between risk, racial, and perhaps gender categories, and utilization and survival outcomes of AIDS.

References

1. George R. Seage III, Stewart Landers, M. Anita Barry, Jerome Groopman, George A. Lamb, and Arnold M. Epstein. "Medical Care Costs of AIDS in Massachusetts," JAMA 256, no.22 (Dec.12,1986):3107.

2. George R. Seage III, Stewart J. Landers, M. Anita Barry, et al. "Costs of Medical Care for AIDS in Massachusetts: Trends Over a Two-Year Period," (Poster Presentation WP.210) at III International Conference on AIDS (June 1987).

3. George R. Seage III, Stewart J. Landers, M. Anita Barry, et al. "Temporal Changes and Institutional Variation in the Cost of Treating AIDS (Abstract). IN: IV International Conference on AIDS. Abstracts Vol.2. Stockholm: Swedish Ministry of Health and Social Affairs, 1988:413.

SEATTLE-KING COUNTY: A MODEL PROGRAM FOR HEALTH SERVICES DELIVERY

Patricia McInturff, Director, Regional Division, Seattle-King County Department of Public Health

DEMOGRAPHICS OF KING COUNTY WASHINGTON

- 2,134 Square Miles
- Population 1.4 million (30 percent of State) 2/3 Urban or Suburban
- Includes Seattle (population 491,000)

AIDS IN KING COUNTY

- First Case in 1982
- 685 Cases Through July 1988 (74 percent of State Cases)
- Projections

1988:	469 New 516 Surviving	1995:	2300 New 4300 Surviving

RISK GROUPS IN KING COUNTY

86%	Homosexual/Bisexual Male
1%	IV Drug Users
10%	IV Drug User and Homosexual Men
1%	Hemophiliac
1%	Heterosexual Contact
1%	Transfusion

HISTORICAL PERSPECTIVE

1. University/Health Department/Community Alliance for STD Since 1973
2. Gay Community and Local Government Alliances (since 1972)
3. First AIDS Case Identified in 1982
4. Mid-1983: Local Funding of AIDS Project (8 cases)
5. 1985 Seattle AIDS Task Force: To Develop Integrated Approach to Housing, Health Care, Social Services
6. Robert Wood Johnson Funding

    a. Application process unified, stimulated ideas
    b. Implementation: coordination of services

WHAT WAS UNIQUE ABOUT OUR HISTORY?

1. Pre-established relationships and alliances that could be built upon
2. Early commitment by government
3. An organized, politically savvy gay community
4. Establishment of a framework for development of an integrated system
5. Commitment to anticipate rather than react
6. Early leadership by Public Health Officials

AIDS/ARC CONTINUUM OF CARE

Setting:	Array of Services:
Multi-Site	Case Management
In Home	Homemaker/Chore, Attendant Care, Home Health Hospice, Counseling/Emotional Support
Community	Hospice, Counseling/Emotional Support, Nutrition, Information/Referral, Resource Advocacy, Legal Assistance, Transportation, Housing, Financial Assistance, Spiritual Assistance, Touch Therapy, Testing/Assessment/Diagnosis, Treatment-Ambulatory
Physician-Directed	Testing/Assessment/Diagnosis, Treatment - Ambulatory, Treatment - Acute Care Hospital
Institutional	Treatment - Acute Care Hospital, Intermediate Care Facility, Skilled Nursing Facility, Mental Facility
Other	Prevention/Education, Research, Data Collection/Analysis, Dental Care

REQUIRED SERVICES

1. Continuum of Care: Full spectrum of education/prevention, medical and social services
2. PWAs maintained in least restrictive setting
3. Coordinated medical care and social service managers for each PWA
4. Multidisciplinary teams for inpatient and outpatient care

5. Medical evaluation available to all seropositives
6. Timely services with emergency response capability
7. Financially feasible system to accommodate all who need services

GUIDING PRINCIPLES

1. Health Department Leadership Role

   System Development
   System and Service Coordination
   Advocacy for Service Needs

2. Centralization vs. Decentralization of Services

   Case Load Alone Will Require Sharing By All

3. Relevant and Culturally Diverse Services and Approaches

   IVDAs and Their Sexual Partners
   Prostitutes
   Street Youth
   Children
   Mentally Ill
   Other

4. Distribution of Financial Responsibility

   Public Responsibility
   Pursue Private Resources

ORGANIZATION OF SERVICES

1. Use existing organizations and systems
2. Find appropriate organizations and/or work to modify existing systems
3. Lead agency approach to resource identification

   Solicitation
   Appropriation
   Targeting Resources

4. Tiers of Organization

   Strong Lead Organization for Each Component
   Promote Accountability
   Promote Strong Organization

5. Avoid duplication, assure coordination, encourage innovation and testing of new ideas
6. Use and expand strong volunteer network

UNIQUE FEATURES OF THE KING COUNTY MODEL

1. Broad Consensus on Principles, Services and Organization Structure; Community Input
2. Lead Agency Approach
3. Social Services Case Management
4. Diversity of Options for Services
5. Strong Volunteer System
6. Politics of Inclusion

EVIDENCE OF SUCCESS

Hospital Charges and Length of Stay - Washington State

	1984	1985	1986	1987
Number of Hospitals	61	228	269	374
Mean Length of Stay (Days)	18.4	13.2	11.3	10.6
Mean Charges per Admission ($)	13,004	9,031	6,981	6,878

FIVE YEAR PROGRAM PLAN

1. To present a picture of where the AIDS epidemic is headed in Seattle-King County over the next 5 years (through 1993)

2. To outline the prevention activities and health care and social support services which should be in place to respond to the epidemic and where gaps in or problems with availability or access in these will occur

3. To identify how these deficiencies will be addressed and where the resources will come from to accomplish this

"AIDS is unprecedented health problem and is going to require unprecedented solutions and approaches. Things that people consider to be impossible or inconceivable in other contexts may very well become possible in the context of AIDS."

Dr. Johnathan Mann

METROPOLITAN AREA HIV SERVICES (MAHS) PROJECT -- A HRSA FUNDED AIDS SERVICE DEMONSTRATION PROJECT IN BOSTON: A PROGRESS REPORT.

Martha W. Moon, MAHS Project Coordinator, Clinical Director

The Metropolitan Area HIV Services Project (or MAHS) is a HRSA funded AIDS Service Demonstration Project in Boston, Massachusetts. The MAHS Project is coordinated by the Fenway Community Health Center in conjunction with the AIDS Action Committee of Massachusetts, Dimock Community Health Center, Boston City Hospital, and the Visiting Nurses Association of Boston. The project is funded for a 3 year period beginning September 1, 1988 through September 30, 1990.

Over this 3 year period the MAHS Project will provide a community-based service delivery network for up to 8,500 people with HIV infection, ARC, or AIDS. The entire Boston SMSA will be served through the creation of ambulatory service teams that will expand community based care in participating community health centers and home care agencies. The SMSA accounts for 64 percent of all Massachusetts cases of AIDS to date and Boston hospitals have provided 80 percent of inpatient AIDS care. Most components of the project concentrate on the development of services in the Boston area in years 1 and 2 with expansion of services to other cities in the SMSA occurring during year 2 and 3.

One of the objectives of the MAHS project is to increase early HIV identification and diagnosis by facilitating coordinated development of a medical, mental health, and support service case management system. This is a project-wide goal of all participating agencies holding subcontracts for services. It enables coordinated service planning to ensure community based service delivery.

An intensive effort is being made to increase the access to early health care at minority community health centers through the efforts of an HIV health educator available to rotate through these centers and reach high risk partners of intravenous drug users and women at risk for HIV infection. This health educator works closely with other health educators and planners throughout the city to organize educational programs which target at risk populations in minority communities. For example, she has just recently developed an HIV education program to be integrated into the Teen Clinic at several of the minority community health centers in the city.

Another objective of this project is to decrease the number of bed days for people with AIDS in the Boston metropolitan area by 10 percent, by decreasing the service delivery of hospitals and increasing the service delivery of home health care providers and ambulatory health providers. This objective is being met by the creation of two medical service teams, one based out of the Fenway Community Health Center and one based out of Boston City Hospital. These

teams will be available on a rotating basis to participating community health centers for technical assistance to primary care providers; on an on-call basis for rapid admissions and discharges of PWA's from area hospitals, and on a consultative back-up basis for nurses administering intravenous drug infusions at home and in the HIV Treatment Center at the Fenway Community Health Center.

The third objective of the MAHS project is to increase the capability of ambulatory mental health service delivery for people with HIV infection by stimulating the development of a comprehensive mental health network. The focus of this portion of the project is to generate the baseline data not currently available on mental health systems for people with HIV infection during year 1; and promoting the development of replicable group formats for people who have tested positive for HIV, families, and significant others of people with HIV infection in existing systems throughout the SMSA in years 2 and 3. A mental health resource developer is based at the AIDS Action Committee to implement this objective.

The fourth objective is to improve the home based care delivery system currently managed by the 5 area Boston Visiting Nurses Association agencies and several private home care corporations for people with AIDS. Two home care resource coordinators have been hired t implement this. One is based at the Boston Visiting Nurses Association and is responsible for developing coordination among Boston based home care and hospice organizations. Another home care resource coordinator is based at the AIDS Action Committee and is responsible for developing coordination among other SMSA home care organizations.

The fifth objective of the MAHS project is to increase the housing available for people with HIV infection in order to achieve a substantial reduction in bed days at area hospitals for PWAs. A housing resource coordinator is based at AIDS Action Committee to implement this.

The MAHS Project is fostering greater cooperation of a new loose association of community health centers, home care agencies and social service providers by expanding the type and level of community based care available and commitments of area providers to serve those with HIV infections. It will enable these networks to successfully transition patients from medical outpatient settings to inpatient hospital services and back to community based outpatient or home care settings. It will ensure a continuity of care from entry of a person with HIV infection into the MAHS system through stages of care consistent with their needs. MAHS will enable a savings in public and private care dollars that will promote this service demonstration project as desirable for replication with modifications in other areas.

PRIMARY CARE ISSUES

Anthony Scarsella, Pacific Oaks Medical Group, California

In 1980, our primary care practice in Los Angeles was responsible for reporting one of the first cases of Pneumocystis Carinii Pneumonia. Within months, more opportunistic infections began to appear in our largely homosexual practice population. The epidemic had begun in Southern California. The next 4 years saw the development of many problems, not all of them in the technical aspects of the disease.

Within 2 years, after the extent of the illness became apparent, our group found itself caring for a substantial percentage of the private patients in Los Angeles and overwhelmed by the disease. The steadily increasing patient load and the lack of services available from the surrounding medical community forced our group to re-evaluate our approach to AIDS care.

At that time, the medical specialists in the community were not accustomed to the disease. They were, therefore, somewhat fearful of treating patients with AIDS. In fact, it was not uncommon for a hospital and its support staff to segregate a PWA from the other patients, hoping to keep his/her presence as quiet as possible.

Our group, along with countless others, realized that PWAs often had no support group to turn to, not even their families. This led to the formation of an organization, co-founded by Dr. Joel Weisman, known as AIDS Project Los Angeles (APLA). APLA's goals are in line with our group's aims to sustain the very ill, educate the well population at risk, and establish programs intended to stop the spread of the disease.

As the epidemic grew, our group, led by Dr. Eugene Rogolsky and Dr. Weisman, began to search for a hospital which would agree to support the development of an Immune Suppressed program. We knew from experience that educating the hospital staff was critical. We spent long hours speaking to hospital administrators, nursing staffs, and physician specialists. Sherman Oaks Community Hospital, in the San Fernando Valley, agreed to support the development of our treatment program.

Choosing a nursing staff for the unit was an important, time consuming project. We had to decrease the entire hospital staffs level of fear through education. Once the hospital staff, as a whole, learned more about AIDS, we were able to establish a knowledgeable, capable and compassionate nursing staff which could provide support services to these patients and their families. The Sherman Oaks Immune Suppressed Unit became a place where PWAs felt comfortable and properly cared for.

From the start, we recognized the need for research. Two of our local universities, the University of Southern California (USC) and the University of California at Los Angeles (UCLA), began to develop research and treatment centers. Since our group had developed experience and a reputation for the treatment of patients with HIV infections, these universities invited us to join their teaching staffs. Our purpose was to educate residents and medical students about AIDS based upon our direct care giving experiences.

This subspecialty direction was unexpected for a primary care group. But in contrast to many cities, care of AIDS patients in Los Angeles was not concentrated in the university or the public hospital. Initially, we hoped that the San Francisco experience, in which the University spear-headed both research and treatment, would be repeated. This did not materialize locally. Our universities' programs were, for the most part, strictly research. Any care they would supply came through the LA County Department of Health in public hospitals. It was quickly overburdened. Whatever the economic or political reasons, a single university directed program did not exist to act as a center for practicing clinicians.

It became evident that the total care of a PWA was not being addressed by the universities or the public hospitals. Our universities did not initially integrate care. The care was, instead, scattered between competing departments. Our primary practice was, by definition, an integrated service. The subspeciality model of care offered at the universities was confusing to the PWAs who went to them for care. We realized that our management of patients provided the continuity to see a patent through all aspects of their illness. We found our clinical knowledge extended enormously by those routine patient visits. We were also able to pick up developing problems more easily because of that continued contact with the patient.

While all of the technical aspects of care were developing, we recognized that our patients required psychological and social service support. Turning to the hospital, we established a social worker dedicated to our patients. Psychologists were invited to see patients in our offices. Within months, it was evident that the psychological and social services had to be offered in both outpatient and inpatient settings. These services matured rapidly. Our group had become a total care center for treating PWAs. Regular multi-disciplinary unit meetings have been held for the past 2 years to ensure that a PWAs total health care is being reviewed and coordinated.

We feel it is time to formally organize some type of "AIDS" board based on the model of community tumor boards. This board would serve as a vehicle to spread information and give advice to primary care physicians who may care for only a few AIDS patients.

Within the last 6 months, the universities have begun to develop ways for the private community to share research protocols. We are happy to say that we initiated those contacts and now find ourselves working closely with the researchers. Further, we are suggesting research subjects which we know

would refine the primary care of our patients. The universities have been very interested in developing the protocols with us.

It is apparent that much of the leadership responding to the epidemic has come from the private community. That community is attempting to develop a consortium to connect the centers of care and provide a very large base for potential research programs.

Within our group, we have incorporated the services of social workers, psychologists and dietician specialists under one roof. Because the system is private, we have been unable to rely on compensation from the insurance companies for many of the services we feel are necessary to our patients. All of the physicians in our group feel so strongly about the need for these services, chiefly psychological and social work, that we long ago decided to absorb any uncompensated expenses.

As the treatment becomes more complex and as we initiate therapies earlier, we have found that we have to work directly with the major insurance companies, educating them and explaining the reasoning for the therapies we recommend. Like the earliest days of cancer care and chemotherapy, these companies have found themselves bewildered by the many therapies available. This lack in knowledge has led to frequent denials of care or therapeutic regimens. We have found it necessary to begin working with "managed care" programs in some of the insurance companies to ensure that all of our patients needs are met.

What began as a response to the emerging epidemic has developed into a primary care model that delivers highly specialized services to a particular group. Everything we have done has been in response to perceived needs. The speed and flexibility of our response is unique to the private medical community which does not have to deal with the necessary bureaucratic deliberation of the university on the public health services. In short, we are free to respond quickly.

Since our practice has been centered on the homosexual community, our drive to make the best response and to provide the best care for our patients with AIDS has not wavered.

DEVELOPING HIV SPECIALTY SERVICES IN AN ACADEMIC ENVIRONMENT

Ronald O. Valdiserri, University of Pittsburgh, Falk Clinic Laboratories

Much has been written about the importance of developing clinical services to meet the needs of persons with symptomatic HIV infection. In addition to the complex medical problems of these individuals, which often require the expertise of a number of different physician specialists, patients with symptomatic HIV infection may also experience significant psychiatric illness. Even if they don't require the services of a psychiatrist, these persons may need ongoing psychosocial support to cope with the fear, anger, and despair which frequently accompany HIV infection.

Optimally, service delivery systems for the care of persons with HIV-related illness should also include community-based supportive care. Experience from communities with large numbers of AIDS patients documents the importance of community-based organizations in providing practical support for such activities as transportation, shopping, cooking, and cleaning. These services must be coordinated with and integrated into the medical and psychosocial care giving.

While estimates of the number of persons in America who are infected with HIV vary, growing evidence suggests that a majority of all infected individuals will develop some form of symptomatic illness, and current predictions of a quadrupling of (cumulative) AIDS cases by 1991 further strengthen the urgent need for prospective planning of health related services.

This brief report relates the experience of developing a model for delivering clinical services to HIV infected individuals at the University Health Center of Pittsburgh, Pennsylvania. Metropolitan Pittsburgh has a population of approximately one and one-half million people. The community has a relatively low incidence of AIDS. As of July 1988, there have been 189 cumulative cases of AIDS in Allegheny County. Despite the relatively modest number of diagnosed AIDS cases, the region has been quite active in AIDS-related research. The University of Pittsburgh has been the recipient of several federally funded AIDS-related research grants including the Multi-Center AIDS Cohort Study (NIAID), the AIDS Clinical Trial Group (NIAID), a Centers for Disease Control funded AIDS risk reduction project, and a clinical trial of anti-retroviral drugs for the treatment of HIV-infected hemophiliacs. Recently, the Health Policy Institute of the University of Pittsburgh initiated a comprehensive planning study of the consumption of health care resources by AIDS patients in western Pennsylvania. The region also has a number of community-based AID-related organizations, including a local AIDS Task Force.

The initial impetus for the need to revise clinical services to meet the needs of HIV infected persons came as a recommendation from the project manager of

the University's ACTG. Although the ACTG does not provide primary medical care to the HIV infected participants enrolled in its clinical trials, project staff are in close contact with referring health care providers and routinely make medical, dental, and psychosocial referrals for volunteers. Based upon their experience, several problems became apparent.

Although the physicians available for treating HIV-infected patients in the area were adequate for current needs, the number of physicians who expressed willingness to provide primary medical care to persons with AIDS was actually quite small, and deemed to be inadequate for future needs. Also, it became apparent that these patients required a great deal of time from the care provider, not only for the diagnosis and treatment of their underlying medical problems, but also for ongoing support and reassurance. Finally, many of these patients were seeing a number of medical specialists and it was often difficult to coordinate information and care across various care providers.

In response to these concerns, and recognizing that the number of persons with AIDS would increase in Allegheny County (the Pittsburgh MACS reports an HIV seroprevalence rate of 20 percent among its 2500 gay and bisexual volunteers), a project team was established to look into revising clinical services for HIV-infected patients at the University Health Center of Pittsburgh. This team consisted of representatives from the following areas: departments of medicine, psychiatry, and infectious diseases; the ACTG investigative and clinical staff; the Allegheny County Health Department; and the administrative and social service departments of Presbyterian University Hospital and Falk Clinic. Presbyterian University Hospital and Falk Clinic are the University's adult hospital and ambulatory care facility.

The proposed model has the following objectives: to integrate medical and psychiatric care, social support, and community services; to emphasize ambulatory care with close coordination between inpatient and outpatient care; to make extensive use of mid-level clinicians (nurse practitioners and physician assistants) as physician "extenders" and patient "managers"; to develop bidirectional linkages with University-based research programs; and to formalize linkages with community-based service organizations for the purpose of bidireactional referral. The model was based on both local and national antecedents. Apropos of the latter, the experiences of San Francisco and Los Angeles were given special consideration.

The model designates the nurse practitioner to act as the patient manager, coordinating care across different practitioners and different episodes of inpatient and outpatient care. Upon entry into the program, each patient will have an extensive medical, neuropsychiatric, and psychosocial evaluation so that a care plan can be developed. Routine ongoing care will be provided by the nurse practitioner under the supervision of the clinic's medical director, a designated University physician who will be responsible for the initial medical evaluation, supervising the nurse practitioner, and consulting with him/her on problem cases. The model also includes a designated social worker and psychiatric consultant. The other medical consultants will be selected from the

specialty programs housed within Falk Clinic, and referrals will be made "in-house".

This model differs from the way in which care is usually delivered to AIDS outpatients (at the University of Pittsburgh), who generally see a number of different attending physicians and/or housestaff. For example, between July 1986 through September 1987, 39 outpatients with AIDS or ARC accounted for 119 outpatient visits. They were cared for by 23 different attending physicians and on average each patient saw more than two different physicians during that period of time (range 1-9).

The potential benefits of this model include: greater integration of multiple speciality medical care; greater integration of supportive care with medical and psychiatric care; a more cost-effective use of physician's time; decrease in the number of hospitalizations; decreased hospital length of stay; improved clinical outcome with earlier intervention; "watchdog" function for unapproved treatments; impetus for the development of community-based services; and improved access to potential candidates for experimental clinical trials. There are also potential disadvantages to the proposed model. Some of these disadvantages, such as possible adverse reactions from clinical staff and other patients, can be minimized through appropriate training and education during the implementation period. However, the potential for negative financial consequences, especially if the facility attracts mainly "end-stage" patients, is not possible to quantitate at this point in time.

Administration has recently granted approval for funds to be released to implement this model on a trial basis. Although this model is not yet evaluable at an outcome level, it is possible to descriptively evaluate several of the process issues, especially those related to planning. Several barriers to planning were encountered, though none proved to be insurmountable. The small number of diagnosed AIDS cases in Pittsburgh and the subsequent noncrisis environment tended to give the impression that changes in the status quo were not necessary. Because of the large number of individuals who collaborated on this project, differences of opinion had to be addressed, and although consensus was ultimately reached, this process required time, diplomacy, and the ability to negotiate. Our experience indicates that there may be no immediate financial benefits to changing the status quo (although there are potential future benefits). This can also serve as an impediment, especially in environments where cost control is of primary importance. It is most likely that the presence of broad based support for the concept of this proposal along with the presence of local "fixers" was largely responsible for its funding.

THE C-100 CLINIC: A PROTOTYPE FOR HIV-RELATED PRIMARY CARE IN A SOUTHERN PUBLIC HOSPITAL

Ted Wisniewski, Charity Hospital, New Orleans, Louisiana

On June 15, 1987, the C-100 Clinic opened at Charity Hospital of New Orleans (CHNO) to house a growing number of outpatient programs developed in response to HIV. The following summary reviews the history of AIDS care before C-100, the components of a centralized primary care program, and some conclusions realized after 1 year of implementation.

HISTORY OF AIDS CARE AT CHARITY HOSPITAL OF NEW ORLEANS

In order to describe the real difference that primary care makes through the C-100 Clinic, it is helpful to understand a bit more about Charity Hospital.

Charity is the oldest hospital in continuous operation in the United States, coming into existence in 1736. This remarkable institution has endured kings and kingdoms, floods, fires, hurricanes, political machinations, international rivalries, and all out war. The motto inlaid in its lobby floor reads "in this harbor, weary sea-worn ships drop anchor and new launched vessels start their outward trips; within these walls life begins and ends."

Today, after 252 years of service, Charity Hospital remains as the single system for care for all persons without third party payment mechanisms in the State of Louisiana. Private hospitals here do not share the cost of indigent patients as seen in many other States. State medicaid only pays for 15 days of private hospitalization and, even if medicaid eligible, it often takes many months for patients to broker the bureaucratic maze of securing this benefit. As of this writing, there is still no New Orleans city budget for AIDS. Until a recent AIDs budget was approved by State legislators in July 1988, all State monies for AIDS were provided through Federal or CDC grants.

Charity maintains 600-750 beds depending on budgetary constraints. Last year, 30,000 patients were admitted to the hospital and over one-half million were seen by the outpatient department. Access to this care system is through the emergency room where the usual wait is between 18 and 24 hours. If deemed "sick enough", patients are either admitted to the hospital or given a follow up appointment to the clinic system. Most people are simply discharged. Once brought into the Charity system, direct care is compromised by nursing shortages in almost all departments. It takes 2 months to secure an outpatient CAT Scan of the head, 6 months to obtain a dental appointment, and 8 months for routine follow-up in the medicine clinic.

Charity Hospital is, therefore, a typical large tertiary care center with two medical schools -- Louisiana State University (LSU) and Tulane University --

holding the contracts for the vast majority of physician staff. One of the most challenging aspects of the C-100 project has been trying to set up an administrative structure that prioritizes patient care from a community-based perspective in the midst of a system with major priorities in academic medicine and research.

The initial stimulus and on-going drive in establishing a primary care system at Charity Hospital comes out of the New Orleans AIDS Project (NAP) a community-based endeavor funded in November 1986 by the Robert Wood Johnson Foundation as an AIDS Health Services Demonstration Project. With funds for physician and nursing staff, home care and hospice services, two social workers, a health educator, and a volunteer services director, a core team was formed setting one of its bases at Charity Hospital. The early days were caught up in securing office space and achieving legitimacy in an arena directed largely by infectious disease sub-specialists.

A central focus of the infectious disease sections was the initiation of a recently funded National Institutes of Health (NIH) AIDS Treatment Evaluation Unit (ATEU). (Note: This is currently called the AIDS Clinical Trials Unit - ACTU). With far greater staff and funds provided to the ATEU, the building of an effective comprehensive care system seemed only a dream. With limited space available, NAP and ATEU staff shared working space as well as common patient population and thus, engaged one another regularly. The pride of our first 6 months was the cooperative spirit that developed among the combined staff. ATEU study nurses presented friendly faces and energetic spirits to the NAP team of providers who, at that time, already felt some weariness from years of volunteer activity with the NO/AIDS Task Force community service organization.

What evolved over the period of about 6 months were four inter-related systems sharing the same clinic space. These included the NAP Primary Care/Continuity Clinic, three half-days a week; the Infectious Disease Clinics, one half-day a week for each medical school; and the Charity Clinic for ATEU protocols, staffed by a volunteer team of mental health professionals from LSU providing weekly comprehensive evaluations for study protocol and primary care purposes. A chemotherapy clinic and an IV/Respiratory therapeutics station were recently added. Much energy and negotiation was put into developing patterns of inter-referral delineating responsibilities for various aspects of patient care.

With time, the Primary Care concept won the trust of the patients, the medical schools and the hospital. In less than a year after we opened, the Primary Care Clinic was selected as the official, single intake for the Charity system's response to AIDS. This meant that our team had charge of the initial contact with the patient, the assessment, and plans for AIDS prevention education.

THE COMPONENTS OF THE PRIMARY CARE PROGRAM

Our experience has brought us to describe ten essential elements to a comprehensive Primary Care program for people with HIV:

1. HIV testing/counseling/prevention;
2. Routine HIV-directed intake and follow up;
3. Referral mechanisms to experienced sub-specialties;
4. Clear admission/discharge procedures with inpatient unit;
5. Linkage to home care/hospice;
6. Mechanisms to meet concrete needs/social services;
7. Access to dementia/neuropsychiatric screening;
8. Readily available health education for patients/families;
9. Plan for dual disease of substance abuse and AIDS; and
10. Integration of investigational therapies appropriate to overall regimen of care.

For the patient who is self-motivated and requires only routine health care services, this primary care system works fairly well (see Appendix A for routine baseline care plan). Nursing visits and protocol review ensue at 3 and 9 months with a physician visit and blood work every 6 months. Problems are followed up more frequently as appropriate. Most of our patients, however, present with multi-system needs. In order to make a comprehensive care program work for these patients, something has to help steer them through various components. It is our case management system that helps keep people from falling through the cracks.

The term "case management" originates from the discipline of social services and takes on different meanings among various AIDS service-providing organizations across the country. Case managers, currently all of whom are social workers, assess the patients' bio-psychosocial condition and needs using a standard intake format. They then develop a care plan and coordinate the components vital to the success of the plan.

THE FUTURE OF C-100

Looking back, it is comforting to realize that many problem areas have been tackled successfully and that projects once paralyzed by hysteria are functioning with an ever-widening base of support. As the number of patients grows, it seems that we trade old problems in for new ones with our current focus upon inadequate drug supply and an insufficient number of primary care providers (our next available appointment for a new patient is backlogged four-and-a-half months). A general goal we have for the year ahead is to take the Primary Care model implemented by our small, grant-funded team, and systematize it. To do this, we will need further support from the medical schools and the hospital administration. We absolutely need to do this because our small team is already overwhelmed with patient volume in less than a year. Integration of the Delta Region AIDS Education Training Center (ETC), recently

funded by HRSA, into the already functioning programs of C-100, will be a major thrust for the coming year.

What is clear, even after just a year of experience, is that we have put together a system that is working well and delivering quality care for people with HIV. We must step back from the front line of care, monitor our program, make changes where appropriate, and describe what we have experienced to other centers just beginning to gear up for the epidemic. Some of what we have learned can already be described.

CONCLUSION/RECOMMENDATIONS

1. During this initial year of the program, Charity Hospital has clearly chosen a centralized approach to care of persons with HIV. It took us about one year to create a system and develop policy and procedure to address major gaps in the hospital/tertiary medical center system. Having done so, we now are looking to incorporate the ETC, rotating trainees and others in the expansion of our model. It will probably take another year or so before full scale efforts toward mainstreaming of care can take place.

2. A core team of providers structured in our large tertiary care center can effectively provide comprehensive out-patient management for approximately 300 persons at all stages of HIV-related infection. With a goal of 1000 new intakes for the coming year, increases or adjustments in staffing patterns will need to be provided to assure high quality care at these higher patient volumes.

3. It is important to establish a space in which patients can feel comfortable and trusting, and in which the community can experience a sense of involvement/ownership.

4. Clinic administration should be set up to put patient care as a central priority. Articulating this kernel philosophy creates a sense of teamwork among the front line providers.

5. Every attempt should be made to hire personnel with prior direct personal experience with AIDS, provided these persons are not weighted down by burnout or unresolved bereavement issues. Special attention should be given to hiring people who are culturally sensitive, gay-identified, and/or experienced in the field of substance abuse.

6. Sufficient time should be created to allow staff to provide effective responses to each new patient during intake.

7. Time should be structured and built into the work week for staff education, grieving, and group support.

8. A system that is mutually acceptable to researchers and primary care providers requires checks and balances. Administratively, these need to be

separate, but interrelated to allow for clean research and uncompromised care both cooperating in a commitment to patient-centered services.

9. Increased utilization of primary care providers seems most efficient in our experience and we anticipate will result in less duplication of services and lower costs to the health care system.

A commitment to the kind of care described above has many implications. For Charity Hospital, primary care is a new concept in many ways. One thing that lies at the heart of primary care is access -- access to services, diagnostic procedures, medications, experimental and innovative therapies, and most of all, access to a dedicated and caring staff. In addition to advocating for more resources on-site, a goal for the year ahead is to take the primary care model implemented by our small, grant-funded team, systematize it, train new providers to utilize this model, and extend it outward. Anticipating great demand by seropositive persons seeking ongoing care, we are gearing up not only to provide these services on-site but to develop backup mechanisms for other providers across the Gulf south region.

Routine Intake and Follow Up (Minimum)
For C-100 Primary Care Clinic
(For All HIV Seropositive Persons)
With or Without Significant Symptoms)

1. Full History and Physical per general intake form. Full physical exam and documentation updated annually. Modified exam (Retina, Lymph nodes, mouth-minimum) every six months.

2. R.N. Review of Symptoms every three months with appropriate referral to M.D. for new changing symptoms.

3. Referral to Health Educator for review of the following topics:

-- What is HIV Disease/AIDS, education on transmission/handling secretions/safe sex/ IV drug use;
-- Review of research protocols available and services in clinic and community;
-- Review of post-test counseling and appropriate confirmation of + HIV Elisa.

Automatic for all new patients. Follow up appointments PRN or as scheduled by Health Educator.

4. Referral to Social Worker: For medications, social work assessment, situational, illness-related and psychosocial counseling, family therapy, material assistance, referral to case management system.

5. Referral to Case Management Services: Automatic for all with CDC-defined AIDS or those requiring hospice or home health services; on as needed basis for all others.

6. Referral to Research Protocols: ACTU and others where applicable.

7. Referral to One-Time Psychiatric Assessment or Neuropsychiatric Study Clinic when appropriate via Case Manager or Social Worker.

8. Labs/Other Studies:
-- At entry and annually
- CBC with diff. and platelet count, sed rate
- Chem. 16, ALT, Hepatitis B. Surf. AG*, Toxo Titer*, ART
- Selective site GC, urinalysis
- Total T4 and T4/T8 ratio
- Neuro psych screen (mini mental status/timed/gait/digit symbol)
- CXR if any abnormal pulmonary history or complaints
- PPD

-- At routine six month visit
- CBC with diff. and platelet count
- Sed rate, total T4, and T4/T8 ratio
- PPD
- Neuro/psych screen

9. Exceptions:

- More frequent follow up visits or labs will be ordered as clinically indicated.

* Hepatitis and Toxo on entry only (unless specifically requested) 8/1/88

Long-Term Care

A LONG-TERM CARE STORY: FEAR IS MORE CONTAGIOUS THAN AIDS

Kathryn S. Addenbrook, Alan W. Porterfield, Herman M. Wilson Health Care Center; James O. Bond, Montgomery County Health Department

When a resident was diagnosed a possible transfusion associated-AIDS victim, a wave of panic was experienced throughout the facility. The following is a description of the action taken by the facility's administration in dealing with the crisis.

Asbury Methodist Village is located in the metropolitan suburbs of Washington, D.C. A continuing care retirement campus of more than 135 acres is home for over 1,020 residents age 65 and above. The campus includes independent apartment units, a domiciliary, and a 285-bed skilled nursing facility.

Mrs. X, an 87 year-old resident was ordered an ELISA test as part of a diagnostic work-up for her peculiar illness which the physician characterized as progressive dementia associated with extensive oral and perennial candidiasis. The laboratory report simply stated: HIV ELISA Screen: Positive.

That report would be responsible for beginning a sequence of events that would require a concerted team effort on the part of a nursing home staff, the State licensing and certification office, and the local health department officials.

During the first 24 hours, a call was placed to the health department for immediate and total assistance. The immediate advice was to have a confirmatory Western Blot test performed to ensure that the diagnosis of transfusion associated-AIDS was correct. The public health nurse then assembled literature and took this information directly to the nursing home that same day.

An aggressive program was instituted by the facility's administration to communicate factual information to the staff via meetings with every department and to all three shifts. The staff responded with quiet empathy for the resident and her family.

The next morning, it was clearly apparent that our efforts did not stem the mounting tide of fear and anxiety sweeping through the staff. They were refusing to care for the patient. The nursing unit coordinator and the director of nursing fed and bathed the patient that day.

The housekeepers, dietary workers, and maintenance were hesitant to enter the resident's room.

On day three, an impromptu educational program consisting of a panel discussion by the staff (a nurse and a nursing assistant) of a local nursing home who had provided care for an AIDS patient, the State AIDS medical coordinator and nurse specialist. The staff listened politely to the doctor and nurse with their descriptions of AIDS, however, they listened intently to the staff who had provided the actual care. The facility's administration closed the program with the statement that everyone had the knowledge and skill to be care-givers to an AIDS patient. If an employee was unwilling to accept such risks, then perhaps they were in the wrong occupation.

In the question and answer period, most of the questions had to do with whether casual transmission of the HIV virus is possible. Although we emphasized over and over that there are only three known methods (blood, sex, and birth) it still did not convince the skeptics that somewhere down the road there would be new evidence that the virus could be transmitted from contaminated surfaces, clothing, bed clothing, touching, kissing or handling, etc. A concern of several of the staff was whether the virus could be taken home to children. Again, despite assurances that there was no evidence that this was possible, there remained some skepticism. A few questions related to the risk to persons handling the dishware, laundry, or the soiled diapers and flux of the patient.

Following the program, the AIDS physician met privately with the daughter of the patient. She asked many searching questions such as:

- May I continue to feed, touch, and kiss my mother?
  (All of which was confirmed possible and highly recommended.)
- Should she be tested for possible exposure?
- Were any of the grandchildren exposed indirectly?

She expressed concern as to why her mothers' mind had deteriorated so rapidly. She was informed that the AIDS virus might indeed affect the central nervous system.

By the fourth day, the positive effects of the role modeling of care, the educational programs, and the efforts of the administration began to surface. Allied departments offered to assist nursing in providing care for the resident. Nursing assistants were sharing their knowledge of AIDS with their peers. In general, fewer anxious comments were being expressed.

By the end of the week, the staff who had previously refused to care for the AIDS resident were offering their support. The tide of fear, anxiety, and panic had turned. These destructive emotions were counteracted with immediate and prompt education.

A short time later, our AIDS resident died quietly in her sleep before a secure diagnosis of AIDS could be made.

The facility's administration acknowledges the strength, courage, and intelligence of its dedicated nurses, aides, dietary, chaplain, laundry, activities,

social work, and maintenance staff who functioned as a team when faced with a crisis. The knowledge gained by the nursing home staff, the State and county regulatory agencies, the physicians, and the laboratory will serve as a living memorial to this patient and her devoted family.

HOME HEALTH CARE SERVICES FOR PEOPLE WITH AIDS: ENHANCED CAPACITY THROUGH SUPPLEMENTAL STATE FUNDING

Lisa Jeffery, Massachusetts Department of Public Health

In December 1986, the Massachusetts Department of Public Health awarded funds to seven home health agencies and one hospice to encourage the development of services for people with AIDS (PWAs). At that time 418 cases of AIDS had been reported in Massachusetts; approximately 200 were alive. Each of the eight agencies was funded for a 3 year period at an annualized cost of $50,000. They have each hired a person designated to participate in direct care, oversee case management, give support to other staff members working with PWAs, and serve as program coordinator.

The objective of this study is to evaluate each agency's response to the directive of the grant and to monitor utilization rates. The impact of AIDS caseloads on the group of supplemental funded programs will continue to be evaluated and the resulting information will serve as a guide for future resource allocation decisions.

Demographic, service utilization, and program data were collected after the first 6 months of funding to obtain a baseline data set on a fixed number of clients. Thereafter, monthly and quarterly survey instruments were completed by each AIDS Program Coordinator to maintain aggregate caseload and demographic data. Quarterly program assessment tools were also used to evaluate program characteristics, personnel issues, education, and community outreach efforts. Various resource utilization, referral, and payor source data were also collected quarterly. The data resulting from 12 months of monthly and quarterly surveys were then compared to the initial 6 month data set and were generally consistent.

In addition, all 132 home health and hospice programs not receiving funds were surveyed by phone quarterly to assess patterns of service utilization by PWAs. These results were compared to State-funded program statistics to evaluate the effect of funding on service utilization. The following results were obtained from the data collected during the initial 18 months of funding.

For most agencies, a priority upon funding was to educate staff about AIDS in order to reduce anxiety about perceived occupational risk. During the first 6 months, 32 inservice education sessions reached approximately 800 nurses, homemaker/home health aides, volunteers, therapists, social workers, professional, rehabilitation, and clerical staff. Additional sessions were held for the families of agency staff after it was determined that family anxiety about AIDS contributed to some staffs' unwillingness to treat PWAs. The inservices were, with few exceptions, conducted by the AIDS Program Coordinators and covered a wide variety of topics including AIDS epidemiology, infection control,

assessment, treatment, psychosocial and legal issues, volunteer training, and stress management. In subsequent months, an additional 38 educational sessions and updates have reached over 750 health care workers.

During the process of marketing their programs, the AIDS Program Coordinators have become known as community resources. Collectively, they have been successful in educating over 75 community groups about AIDS. Audiences addressed have included other home health and hospice agencies, nursing homes, drug treatment facilities, high school and college students, church groups, singles dating clubs, State agencies, business organizations, union representatives, and a wide variety of other civic groups.

Funded agencies have also been successful in improving referral networks within their communities. These efforts have targeted hospital discharge planners, health maintenance organizations (HMOs), neighborhood health clinics, long term care facilities, jails, and AIDS service organizations. All agencies have reported improved physician contacts in their area and two have signed contracts with area hospitals for the provision of inpatient hospice beds for PWAs in need of acute care services whereby the agency can oversee the plan of care.

Despite a general shortage of health care personnel, most of the agencies have added to their direct care staff as a result of the grant. Half have allocated funds to help finance recruitment of home health aides to work specifically with PWAs. Approximately 30 home health aides have been hired, primarily by placing employment advertisements in gay and lesbian newspapers. Four agencies have hired full or part-time social service workers to facilitate case management and to provide emotional support to both PWAs and their caregivers. Of the seven agencies who employ volunteers, four have expanded these ranks as a result of funding. One geographically isolated agency trained volunteers to become certified home health aides.

In 18 months, approximately 450 people (including 62 percent PWAs, 16 percent ARC, 20 percent other HIV infected, and 2 percent unknown) have been cared for through the eight funded programs. Monthly caseloads ranged from 3 to 58 and have increased an average of 28 percent between October 1987 and June 1988. The average monthly census is 19 clients per agency. The number of new admissions per agency was as high as 16 in some cases, but averaged 3 admissions per agency per month. A total of 116 deaths occurred over the 18 month period. As many as five clients per month died in some agencies but deaths averaged one per month per agency.

Demographic characteristics of HIV-related clients varied widely across agencies, largely due to geographic location. Overall, caseloads were 77 percent male while Massachusetts AIDS surveillance statistics as of June 1988 indicate that 87 percent of reported AIDS cases are men. One agency has treated only male clients, while another had a caseload which was, on average, 41 percent female.

The majority of clients seen by these programs are 30-39 years old; ages range from newborns to over 60 years old. The mean age of PWAs in Massachusetts is also between 30-39 years old. Children under the age of 6 comprised 9 percent of home health agency caseloads (no clients between the ages of 7 and 13 were seen). Pediatric cases of AIDS (<13 years old) account for 2 percent of reported cases in Massachusetts. A 6 month review of 17 pediatric home health cases revealed that 2 (12 percent) had AIDS, 3 (18 percent) had ARC, and 12 (70 percent) were being evaluated for seropositivity. Most were under age 2 and were offspring of an infected client. Infants who had tested positive for the HIV antibody or antigen at birth were routinely followed by an AIDS program. Unless in foster care, most HIV seropositive children were followed in conjunction with care provided their symptomatic parent.

AIDS program caseloads were 61 percent White, 21 percent Hispanic and 17 percent Black. Compared to AIDS surveillance statistics, home health clients were more frequently of Hispanic ethnicity (21 percent vs. 9 percent). Spanish was the primary language of 19 percent of clients, English was spoken by 79 percent and Creole or French by the remaining 2 percent.

Home health clients were more likely to have IV drug use as their mode of transmission than AIDS surveillance statistics would suggest (28 percent vs. 16 percent) and were less likely to be homosexual/bisexual men (49 percent vs. 62 percent). Perinatal transmission is the source of infection for 9 percent of caseloads. Of the cases who had a presenting diagnosis reported (73 percent), the majority (53 percent) had Pneumocystis Carinii Pneumonia listed as their presenting diagnosis, while 14 percent had an altered mental status, 11 percent had Kaposi's sarcoma and 25 percent had various other opportunistic infections.

One-third (33 percent) of home health cases lived with a partner, lover, or spouse, while 24 percent lived with a parent or other family member. A reported 27 percent lived alone which may, at least in part, account for the observation that the intensity of both nursing and home health aide care was greater for HIV-related clients than for others.

An average of 1.6 nursing visits per week are made to AIDS program clients. These visits reportedly take twice as long as those for non-HIV-related clients and range between 1-2 hours for a mean of 1.3 hours per visit. Nursing duties performed during these visits include 33 percent client and family teaching, 30 percent client assessment and 23 percent counseling and listening. Home health aides spend an average of 13.6 hours per week per HIV-related client. Agencies report that home health aide visits take longer than for non-HIV-related cases 83 percent of the time. Over a third of the home health aide's time is reportedly spent on patient hygiene and the rest is fairly equally divided between home hygiene, support/listening, and assisting with mobility and eating.

All eight agencies reported having clients who utilized IV infusion care. An average of 16 percent (3 clients/agency/quarter) of clients needed IV care.

Seven agencies subcontract with IV companies to facilitate home IV therapy to 42 percent of their combined IV cases. Over half of the cases received supplementary services from AIDS service organizations such as the AIDS Action Committee and AIDS Project Worcester.

The length of time HIV-related clients stayed on caseload ranged from 1 day to 78 weeks for a mean of 16.8 weeks. The length of stay was essentially the same for the 25 clients who received care from hospice as it was for home health agency clients. Of the 164 clients who were hospitalized between October 1987 and June 1988, 99 (60 percent) eventually returned to home-based care. The average length of hospital stay was 9.5 days. Over half of HIV-related clients were referred to home health by hospital personnel or hospital-based physicians (60 percent); 12 percent of clients sought out home health services themselves.

Medicaid was the payor source for 65 percent of clients receiving care from an AIDS program. Only 25 percent of HIV-related cases were insured through Blue Cross/Blue Shield, HMOs and commercial insurers. Free care, medicare and "part fee" cases comprised the remaining 8 percent of payor sources; 2 percent were unknown. In some cases agencies reported that they did not submit bills to medicaid because the time lost in billing would have outweighed the reimbursement benefit.

The percentage of HIV-related cases within six of the eight agencies remains below 4 percent. Of the remaining two, the hospice and the most geographically isolated home health agency had HIV-related caseloads of 15 percent and 50 percent respectively. The eight State funded agencies represent 5 percent of the 140 home health and hospice organizations across the State. In contrast, they have served an average of 71 percent of the HIV-related cases receiving home-based care in the past year.

The results of the first half of the funding period show that State-supplemented home-based AIDS programs reach a wide range of people with HIV-related illnesses and that caseloads do not always reflect State AIDS cases' demographics. Efforts to establish these programs as community resources appear to have been successful. Given the current trend toward more IV drug use-associated cases, the number of publicly reimbursed cases are likely to increase as support networks in the home become less common. Coupled with a growing shortage of health care workers, it remains to be seen how long, even with supplemental funding, such a small percentage of agencies will be able to maintain programs which are so resource intensive.

The author gratefully acknowledges Laureen Kunches, Jeanne Day, Eugenia Handler, and the AIDS Program Coordinators for their assistance and support.

CONTINUUM OF CARE IN HOUSING AND LONG-TERM CARE FOR PERSONS WITH AIDS: A CASE STUDY

Andrew J. Kruzich, Project Coordinator, Seattle-King County AIDS Health Services Program.

Seattle-King County's response to the housing needs of persons with AIDS, particularly those with little to no financial or personal support, covers a wide spectrum, including:

- emergency housing (limited stay)
- subsidized independent living (individual and congregate)
- specialized housing (drug abuse therapy, mentally ill, pediatrics)
- long-term care (intermediate and skilled)

All independent living situations provide for home care support and therapeutic services, including home-prepared or home-delivered meals, homemaker and chore services, transportation to medical and social services, home health care, and attendant and respite care as appropriate.

The major factors affecting decisions about PWAs appropriate housing situation include the individual's health status, financial status, personal support system, the community support system, and personal preference. The objective of the Seattle-King County PWA housing program is to maximize independence and maintain persons in a home rather than an institutional environment to the extent possible.

In order to establish this continuum of housing, the Seattle-King County program has recognized the need for the following resources:

- Personnel to plan and develop the housing options
- Capital funds (for purchase, rent, or lease)
- Facilities (new construction or renovation)
- Operating funds (for facilities and services)
- Personnel to assist with placements and interventions

The resources necessary to develop this continuum of housing are jointly provided through the Health Department and the Northwest AIDS Foundation, the major community-based AIDS agency. While the Health Department is responsible for facilitating the development of long term care services, the Northwest AIDS Foundation is responsible for facilitating development of emergency and independent living housing.

The Northwest AIDS Foundation employs a half-time Housing Developer funded by a Robert Wood Johnson Foundation (RWJ) grant, and a full-time Housing Advocate funded by a Health Resources and Services Administration (HRSA) grant. A second full-time Housing Advocate is being sought through

City of Seattle funds in 1989. The Health Department contracts for a half-time Long Term Care Program Developer with RWJ funds, and is currently seeking a second half-time position through HRSA. These personnel are directly responsible for the planning and development of housing options, housing placements, and interventions. They are also responsible for seeking capital and operating funds and facilities.

Although comments in this presentation are directed toward long-term care, it should be noted that the City of Seattle, the Seattle Housing Authority, local churches, and other community low-income housing assistance programs play a major role in providing emergency and independent housing for PWAs in Seattle-King County.

Planning long term care services, and emergency and independent housing, requires attention to the following:

- type and number of persons to be served
- type of services needed
- number of beds or rooms needed
- type of reimbursement available
- physical environment needed or desired
- sponsorship
- construction capital
- operating finances beyond reimbursement

In Seattle-King County, these issues were addressed through two major studies over the past 18 months: an independent consultant study commissioned by the Health Department and completed in early 1987, and a report prepared by a 25-member AIDS Long-Term Care Advisory Committee established by the Health Department in late 1987. The conclusions of the consultant and the Advisory Committee were very similar, and were corroborated by data obtained through the San Francisco Health Department at about the same time.

The types of long term care needs identified included hospice, skilled care, supervised care (particularly for the neurologically impaired), and specialized pediatric care. The reports went on to define the type of client who would need these services and projected the number of PWAs who would require the services through the next 5 years. A more recent consultant report funded by HRSA and looking at hospital step-down options corroborated the need identified by these reports and further defined the type of patient who would utilize these levels of care.

The projections of need in these various areas resulted in the development of a recommendation for a 35-bedroom skilled nursing facility to serve PWAs and other handicapped persons who require similar care by the year 1990 in Seattle-King County. Other related recommendations suggested that the facility be more home-like than traditional nursing home facilities, that it be owned by a community-based organization and operated by an established long-term care

provider, and that it also provide day care and respite care services for PWAs in the community.

The reports went on to identify appropriate and necessary reimbursement, capital and operating expense levels, and funding resources which include the State Department of Social and Health Services, Federal grants, County block grants, City special population levy funds, and community fundraising through the Northwest AIDS Foundation, the Archdiocese of Seattle, and a community capital campaign.

At this time a community-based, non-profit organization, AIDS Housing of Washington, has been established with support from the Health Department to follow through on the Advisory Committee recommendations. AIDS Housing of Washington has submitted appplication for capital grants to HRSA, the City of Seattle, and King County. An exceptional rate reimbursement of $150/day has been negotiated with the State Department of Social and Health Services. The State health plan has been amended to accommodate the facility, and a certificate of need will be applied for in October. A contract for operation and management of the facility is currently under negotiation with the Sisters of Providence. A community capital campaign will be launched in September, with a $100,000 contribution from the Archdiocese of Seattle and a $40,000 commitment from the Northwest AIDS Foundation's Walkathon in-hand. While far from its goal of an established long-term care facility, substantial progress is being made to implement this program.

A variety of community organizations must work collaboratively to make this process successful, including the local housing authority, city, county and State officials and legislative leaders, persons with AIDS, the gay community, major health care providers, and churches.

Major problems and issues identified in this process so far include the following:

- staff expertise and time
- projecting and substantiating the need
- strategy development and adherence (follow through)
- limitations and needs of existing long-term care providers
- facility and site planning and selection
- obtaining capital and operating funds
- management of client to serve different levels of need
- economies of scale for small facilities
- arguments against additional long-term care beds
- arguments against AIDS-specific services/facilities

MANAGING CHILDREN WITH HIV INFECTION: THE NEW JERSEY CHILD WELFARE EXPERIENCE

Constance Ryan, Coordinator, DYFS Medical Unit, et.al., State of New Jersey, Division of Youth and Family Services and St. Clare's Home for Children; Robert Hadfield, New Jersey Department of Youth and Family Services; Terry and Faye Zealand, AIDS Resource Foundation for Children, Inc., New Jersey

New Jersey has the second highest incidence of children with HIV infection in the nation. The incidence of pediatric AIDS cases directly relates to the significant IV drug abusing population in this State. As of July 1, 1988, 55 percent of the total AIDS cases in New Jersey are within the IV drug abusing population. The child often becomes the index case for a mother who may not know she is HIV positive; this mother may be an IV drug user herself, or (knowingly or unknowingly) the sexual partner of an IV drug-abusing male.

In New Jersey, there is also a distinct geographic distribution to the spread of the disease. Over 60 percent of the cases of HIV infection, for example, are concentrated in Newark and Jersey City. This geographic clustering of infection is consistent, once again, with a relatively high concentration of IV drug users in these cities, coupled with the fact that these cities lie along an easy access corridor into New York City.

The problem of HIV infection has impacted on a number of systems including child welfare. In less than 3 years, the number of children positive for antibody to HIV, with ARC or clinical AIDS, under supervision of the State child welfare agency has grown from 13 to 170. The State child welfare agency, the Division of Youth and Family Services (DYFS) tracks children in all three stages: HIV positive, ARC, and Clinical AIDS. Because of this, the number of cases within DYFS are slightly higher than the reported 145 total cases of pediatric AIDS by the New Jersey Department of Health; reporting of cases to the DOH is based on cases meeting the CDC definitions of ARC and AIDS.

The rapidly escalating problem of pediatric HIV infection in New Jersey has required an innovative and aggressive approach on the part of the child welfare system. Child welfare agencies are committed to the care of children and families who are in need of protection or without necessary supports and resources. The problem of IV drug abuse festering amidst the poverty stricken populations within our society is not a new one to child welfare. Historically, practitioners have worked with children and families at risk for a number of problems; problems which could also be considered as major public health threats, such as child abuse and neglect. HIV infection is one more.

Recognizing that AIDS is both a social and medical problem requiring specialized services which demand a high level of expertise and knowledge, the focus of the New Jersey DYFS has been to collaborate with public health

and medical professionals at the State and local levels. These cooperative efforts have produced significant outcomes. This paper will discuss three concepts which are felt to be integral to a continuity of care model. These are:

- A transitional home model/St. Clare's Home
- A medicaid model AIDS waiver
- Issues related to the development of policies and guidelines for child welfare agencies

St Clare's Home for Children - A Transitional Foster Care Model:

St. Clare's Home is a transitional foster care residence for children with HIV located in New Jersey. It was founded by Terrance Pond Zealand, Ed.D., Executive Director, AIDS Resource Foundation for Children, Inc. and his wife, Faye Zealand. It is the first program of its kind in the Nation.

St. Clare's purpose is to provide a home for those children with HIV who:

- are well enough to be released from the hospital and are in need of foster care placement
- have been placed in foster care but now require respite care.

St. Clare's provides an alternative to a hospital for five children under the age of 6 when critical medical care is not needed. Children are cared for by a professional residential staff assisted by volunteers. The length of stay at St. Clare's is ideally 60-90 days duration with each child subsequently moving on to more long-term arrangement either with family, or in foster care.

Medicaid Model AIDS Waiver - Pediatric Component:

The purpose of this program is to help eligible individuals remain in the community or return to the community, rather than be cared for in a long term facility or hospital. Because of the rapidly increasing numbers of children with HIV, the continuing need for foster care, and the prevalence of children in the HIV positive category known to child welfare, the New Jersey DYFS worked with New Jersey medicaid to also include a pediatric component to this waiver. The pediatric eligibility includes not only children diagnosed as ARC and AIDS but also children under the age of 2 years who are HIV positive. Among the new services which this program offers are:

- reimbursement to foster parents through DYFS for the for the special supervision and care required by these children over and above the normal room and board rate.
- health care services in approved, specialized group foster care homes (such as St. Clare's) for newborns to 6 years of age.

Issues related to Policy Development for Child Welfare:

Conservative estimates of more than 3,000 AIDS cases in children by 1991 coupled with the experience of States such as New Jersey which are already faced with escalating numbers, provide compelling evidence that the child welfare system, its program and policies, will share the responsibility of meeting the needs of these children and families. Decision-making and practice guidelines will need to be developed for staff, and, in particular, for HIV screening and confidentiality of information. Some issues for consideration are:

- the importance of access to medical consultants with expertise in the care of pediatric HIV infection (Pediatrics includes: women, infants, children, and adolescents)

- detailed family and individual history-taking with special attention to risk behaviors/categories

- the child welfare practitioner as a provider of information as well as solicitor of information

- universal precautions/infection control procedures for foster parents, daycare and residential care providers

- no mandatory screening; screening always done with informed consent whenever possible and in conjunction with pre- and post-counseling

- disclosure of information based on "need to know", level of involvement in direct caregiving, and distinction between need to know and need to employ prudent precautions

- increased board rates for persons willing to care for children with HIV and the provision of specialized supports for foster parents (i.e. respite, transportation, babysitting)

Psychosocial Support Services for PWAs

MULTI-FAMILY SUPPORT GROUP FOR TRANSFUSION-RELATED HIV POSITIVE RECIPIENTS

Susanne Wise Campbell, Infectious Disease Service, Memorial Sloan-Kettering Cancer Center, New York, New York

INTRODUCTION

How many articles on AIDS have you seen or read in the past week or month? The amount of material published on AIDS is staggering. Yet one specific population has all but been ignored: the transfusion-related HIV positive recipient. There were approximately 10-12,000 units of infected blood transfused prior to blood programs instituting screening procedures in March/April 1985. Many of the patients who received infected blood died shortly after transfusion due to other complications. Of the patients who survived, many found they were infected after symptoms of HIV infection caused them to seek medical attention. Others were identified and notified through various research studies such as the "Lookback" and Transfusion Safety Studies. Often these recipients would be informed of their HIV status without any counseling or appropriate follow-up support.

This population of patients is unique. They are isolated in two ways: they are an older population, and they are HIV infected. Through our work as nurse clinicians we identified an overwhelming need for starting an HIV positive recipient support group, which we felt should include family members and/or significant others.

Many needs could be identified that could be met in a group setting, such as needs for: intimacy, social integration, reassurance of worth, guidance, assistance, the opportunity for nurturing behavior, and access to new contacts.

OBJECTIVES

Objectives of the group were:

- To decrease the isolation of recipients from their families.
- To educate and reinforce that casual contact could not lead to infection.
- To provide a safe environment in which they could talk about their feelings.
- To provide a forum for the development for peer support.

FORMAT

A group model developed by Levy, Tendler, and Van De Vanter at the Greater New York Blood Program for seropositive donor groups was available to us and needed very little alteration for our population of recipients and their families.

The group had originally contracted to meet for six consecutive weekly meetings for one-and-a-half hours in the early evening.

The majority of the group were older persons in their late 50's to 70 years of age. However, we did have a recipient member who was 26 years old and his wife. An important factor to the overwhelming success of this group was the incorporation of family members into the group. There were five transfusion recipients and five family members who were constant participants. The family members included spouses, siblings, children, and in-laws.

LEADERSHIP

The original group was led by registered nurses with oncology, AIDS, and psychiatric backgrounds who had previous group experience. Supervision at monthly meetings was given by a psychologist, skilled in group intervention.

GROUP CONTENT

The first meeting began with "why we are here" introductions. A confidentiality contract was established which usually includes discussion regarding the use of names and what can and cannot be shared outside the group. Expectations regarding attendance and the admittance of new members during the 6 week period were decided.

Session 1: Health Assessment Status

The educational content of this first group focused on teaching the recipients to more accurately assess their own health status. Participants were told that if they were not sure and were still worried about signs and symptoms to contact their doctors to rule out any potential problems and aid in early diagnosis and treatment. They were also given permission to contact us whenever they needed to. We also strongly recommended that they develop a professional relationship with a physician who was a specialist in HIV infection.

Session 2: Issues of Daily Living

Facts about transmission are reinforced and family members were given information if they did not already have it. The focus shifted on how to live with the uncertainty and to deal with the day to day reality of being HIV positive. The current knowledge of infectivity and transmission is well established. Nonetheless, society has experienced tremendous difficulty reconciling the facts with the irrational fear of AIDS. The group members were encouraged to share the irrational fears and real life experiences about infectivity and transmission. Recipients and families were able to ventilate pent up grievances against the ignorant behaviors of families and friends.

Session 3: Stress Reduction Training

Recognizing the relationship between health and stress, our goal was to increase group members' awareness of their own stress reaction so they could learn and utilize adaptive stress techniques. We used the work of Benson, Bernstein and Berkovec to teach group members progressive muscle relaxation and guided imagery.

Session 4: Communication

It is anticipated that group members will learn not only who to tell but also who not to tell. The group acts as an experimental laboratory where group members practice taking risks regarding the sharing of bad news.

Session 5: Safer Sex

In donor groups, as well as recipient groups, this session is used to discuss safer sex practices. In our mixed group of older people, young couples, and family members, sex was discussed in a somewhat different manner. The needs and expectations are different. We did not need to spend time role playing sexual negotiation or disclosure of HIV status to a potential partner. It's not that they were not sexually active but their maturity gave the problems a new twist.

Session 6: Future Options

This session is meant to complete exploration of the option for continued peer support, whether through a peer support group or referral to other community groups. In this group a peer support group was the only option as there were no other community groups available.

CONCLUSION

The success of the group was mirrored in the decreased isolation of the recipients from their families, their increased knowledge of HIV infection and in finding an environment in which they could talk about their fears and feelings. A personal support network was begun which continues still. Group members have continued to support each other and their families throughout the progression of several of the recipients to more advanced stages of HIV infection.

AIDS AND VOLUNTEERS

Virginia D. Crosby, Corporate Director of Volunteer Services, New York, New York

As a point of reference, let me tell you that most of my work as a director of volunteers has been focused on working with the terminally ill. Prior to my current position at the St. Luke's/Roosevelt Hospital Center, I was the director of volunteers in a palliative care hospital where it was my job to design, recruit, train, and utilize volunteers to work with advanced cancer patients. Most of my background has been in "Death and Dying" - a fashionable topic 7-8 years ago among the avant-garde and curious, but certainly not among my friends who either dreaded to ask me how my job was going, or simply didn't ask me at all, which I suspect happens to you sometimes.

Because of my particular background, when I joined the St. Luke's/Roosevelt Hospital Center I was asked to become a member of the AIDS Psychosocial Task Force to explore what we could do to enhance a patient's stay within our institution. It became abundantly clear immediately that persons with AIDS could profit from many things and that I as a director of volunteers could design a program that might address psychosocial issues, advocacy roles and entitlement, and basically help to lessen the stress of coping with AIDS to anyone wishing this type of support. Where and how to begin was the next issue.

It was apparent from the onset that my "regular" volunteers - (the gift shop ladies)- had no desire whatsoever to work with AIDS patients. That was all right with me as I didn't wish to persuade anyone to work with AIDS patients who might not really want to. I believed that there was a whole corps of caring people within the hospital's community that would very much be interested in working with PWAs. No one else believed it, but I did! Fortunately, I was right.

I would be a liar if I told you that all ran smoothly in setting up an AIDS Friendly Visitor Program. Three years ago most hospitals were still putting food trays outside of patients' doors at meal times; fear and paranoia were rampant. My immediate supervisor was very much against my setting a special program up and my regular volunteers, likewise, were appalled to find that I might be thinking of such a program. However, the administration of the hospital was amenable and so I went to work with a lot of delicate dancing. Slowly and methodically, I began introducing the concept of such a program to key personnel.

I sat down with Administration, Social Work, Nursing, Infectious Disease, Medicine, Chaplaincy, and any other significant personnel. Social Work was my biggest ally and I was fortunate to have the Vice-President of Social Work on my team. Basically he knew through his social workers that the type of program I was suggesting could augment his department's functions, that volunteers

could help in advocacy, and address psychosocial issues. I prepared a grant request, the first of several, to the United Hospital Fund of New York. My request was modest. I wanted a little money to support in my endeavors. That money would provide me with a part-time coordinator, 2 hours in the evening, as it was apparent that many of the volunteers who would be interested in this type of assignment would be working people who could only make it in the evening. I needed money for recreational activity, mailings, food, and movie rentals. My request was accepted and the program began.

Volunteers are recruited through traditional sources: churches, synagogues, corporations, street fairs, flyers, and through non-traditional areas, gay support groups, IVDA support programs, organizations such as GMHC (Gay Men's Health Crisis) and SAGE (Senior Action in a Gay Environment). Once recruited, volunteers are screened. They are selected for their sensitivity, their willingness, their listening skills, their ability to be flexible, their endurance, sense of humor, basically someone who would be a guest at the bedside of a patient; someone who has no agenda other than to provide companionship and support to somebody facing a lengthy often socially unacceptable devastating illness that so far has elided and mystified scientist for a cure. Of course, you never know you have to rely on your own instinct, and turn away people that you don't feel comfortable with.

In fact, what I always say to myself is: " If I were lying in a hospital bed, feeling kind of dreadful and bewildered, would I want this person to visit me?" If the answer is no, then I tactfully suggest that the potential candidate might try another area in which to volunteer. After the screening process, all volunteers go through an orientation which we hold on an ad hoc basis.

The orientation, a pre-requisite to working in the AIDS program, includes:

- The philosophy of the program as it fits into the hospital center;
- An understanding of the illness;
- Up-to-the-minute epidemiology information (always presented by an epidemiologist);
- An overview of current trends, new medicines;
- CDC guidelines;
- Some myths vs. the reality of working with AIDS/ARC patients;
- A psychosocial overview of persons with AIDS;
- A profile of the types of patients they will be seeing -- homosexuals, bi-sexuals, IVDAs -- and the commonalty of death;
- The importance of dignity and confidentiality;
- Becoming too involved - an easy peril for most of us;
- Encouraging the volunteers to be at ease.

Our orientation at St. Luke's/Roosevelt Hospital Center is very short; we hold it in one evening. I've evaluated long orientations, short orientations, ones stretched across 8 weeks, 1-day seminars, and frankly, I do not see any

advantage to stretching them out. A couple of years ago I attended a Hospice Workshop at Yale, New Haven Hospital and they stressed that there is a danger in making a volunteer feel overqualified. They loose their spontaneity. I might add that I think the "hands on" experience is invaluable. After the volunteers go through the orientation, they spend their first few visits on the unit with either a staff person or another volunteer and have the option of continuing that for as long as they like.

In the interim, all patients are interviewed to ascertain their desire for volunteer support and if they indicate such, efforts are then made to match volunteers and patients with similar or compatible interests.

Now, you must wonder, what do the volunteers actually do? When we started the program, I invisioned volunteers sitting by patients' beds talking quietly. Now, I ask myself, what don't volunteers do? Volunteers report once a week, no more, except under unusual circumstances. The volunteer is given a list of patients to visit, many of them repeats from the week before. A log is kept by patient name in the volunteer office and before the volunteer goes home, she or he writes up a small descriptive analysis of their visit. Nothing is ever written that could be construed as a breech of confidentiality. The log is simply kept so that the next volunteer who goes to visit the same patient has some knowledge of that patient. The log might indicate how a patient is feeling or that they like pizza, or baseball, or opera. I'd like to add here that the volunteer comments and observations are often included in the weekly psychosocial task force meetings and as a result some changes have been made. Volunteer input has helped in pinpointing certain problems.

Volunteers have fed, held, buried patients from all walks of life: gays, bi-sexuals, IVDAs, men and women who have had either highly professional jobs or who have been homeless. They have in some cases worked with boarder babies, as well, who have tested positive. They feed the babies, talk to them, sing, change their diapers and give them big squeezes and hugs.

If you are starting a program some of the things you might consider are:

- Bedside visiting, feeding (particularly patients who have difficulty eating and who may take a long time or need a little coaxing), sitting with a patient who is scared or near death, holding their hand.

- Follow-up home visits or telephone calls, establishing a telephone reassurance line.

- Training volunteers in advocacy roles, around jobs, landlords, issues of discrimination.

- Training volunteers in entitlement assistance, i.e., medicaid forms/routes, hooking up into the various community support programs available, insurance claims.

- Escorting patients to or from physician visits, clinic visits, treatments.

- Recreational activities, e.g., movie night on a hospital unit or in a clinic waiting area, seasonal parties, birthday celebrations, anniversaries, creative cooking classes to emphasize calories and healthy meals, games, cards, crafts, Sunday brunches.

- Assisting a patient with burial plans, making arrangements for a pet, plants.

When we started the program, we had 18 volunteers and 12 patients. Now we have 40 volunteers and a daily census that has reached over 60 patients. We have scattered-bed patients as well as a designated unit.

Volunteers who make home visits average 500 plus visits in any one month. We have had 94 deaths in our program since January. Our volunteer turn over rate is low. Do I support the volunteers enough? I would certainly have to say no, there is no way that I can, but as I said, the turn over is very low. We have monthly support meeting, but they tend to be sparsely attended. The people drawn to the program are indeed very special and seem to endure.

One of my volunteers who is a well known novelist wrote the following:

> "Not once have I ever known the fulfillment I feel as a volunteer. Nothing in my life has ever made me feel quite so useful or that I was doing something that mattered, or that I was truly giving something of and from myself."

..and likewise from a patient I received the following:

> "I am now at St. Luke's 14 days and will be here another week. The volunteers have been so wonderful; when I had high fevers and trouble breathing they were always there at the right time with the right words..God bless you all".

A THREE-SESSION PSYCHOEDUCATIONAL GROUP FOR HIV-SEROPOSITIVE INDIVIDUALS

Michael Gross, Robert Carr, Massachusetts Dept. of Public Health
Shelley Bruaer, Abe Feingold, Patricia Giulino, AIDS Action Committee
Lee Ellenberg, Fenway Community Health Center
Allan Tweedy, Gay and Lesbian Counseling Service

OVERVIEW

For people who have tested HIV antibody-positive, a three-session group has been developed that combines education and psychological support. Led by a mental health clinician and a health educator, the group seeks to reduce anxiety and a sense of isolation among its members, to offer information about medical follow-up and risk reduction, and to provide appropriate referrals. Affective outcomes are being monitored using a standardized psychometric instrument, the SCL-90R. Group members complete an evaluation of the program content.

OBJECTIVES

The program was designed by a consortium of private agencies providing AIDS services and the Massachusetts Department of Public Health AIDS Program in response to increasing requests for information and support from individuals who had tested HIV antibody-positive. Although ongoing support groups remain important, not all individuals seek this form of assistance: they may not be aware of what a support group has to offer, may be unwilling to commit for a contracted number of months, may find a drop-in group too unstable in membership or content, or may not feel ready to deal intensively with HIV-related issues. Those who have sought long-term groups often have had to wait many weeks for such a group to begin. The model was designed to satisfy the following primary objectives:

- to respond to people quickly and with minimal barriers
- to reach as many antibody-positive individuals as possible
- to offer support, decrease anxiety, reduce isolation
- to provide consistent educational content
- to further assess long-range psychosocial needs of the seropositive population
- to triage seropositive people to support groups and other community resources

LOGISTICS

Sites have been identified that are public (e.g., a university) and, where possible, not associated with a church, hospital, health department, or gay-identified organization, in order to be welcoming to a heterogeneous population. The site of the group is not advertised in order to prevent possible disruption and to maintain some degree of confidentiality. Participants are referred by counselors performing HIV testing in State-sponsored programs, AIDS hotline staff who can screen callers for appropriateness, community medical and mental health clinics, other treatment settings, and private medical practitioners.

STRUCTURE

After a statement of ground rules (e.g., confidentiality) and brief introductions, Session I reviews medical basics of HIV seropositivity in question and answer format, focusing on test protocols, the question of infectiousness, and prognosis. Specific questions about treatments and medical follow-up ordinarily are deferred to Session III. A volunteer speaker who received a positive antibody test result many months earlier describes what he or she has done since learning these results, how that knowledge has changed (and not changed) the way he or she lives, and his or her personal outlook. That testimonial both validates some of the painful feelings participants may be experiencing and also offers hope that in time they will pass. Group members recount their reasons for seeking the antibody test, the circumstances of learning their test results, and their current feelings about that information.

Session II focuses on transmission and safer sex, beginning with a brief review of the fundamentals of risk reduction (safer sex, needle sterilization) that largely takes its cue from the questions group members pose and the worries they express. Because the news of a positive antibody status often is experienced as an assault on the sexuality of group members, an affirmative attitude about sex is taken when clarifying and reinforcing risk reduction guidelines. The session focuses on how to negotiate safer sex effectively, and how to inform past and current partners, where appropriate, of their possible exposure.

Session III on health maintenance discusses the need for ongoing health care and qualities to look for in determining a health provider, personal health maintenance, the importance of medical follow-up (e.g., TB screening, syphilis testing), treatment options, and support groups and self-help programs in the community. Discussions usually center on members' feelings about health providers, confusion about treatment choices, and uncertainty about the significance of cofactors. Participants are offered a list of specific resources and referrals, and other printed materials concerning the topics covered by the program.

OUTCOMES

Across the groups, disclosure has been a recurrent concern. Participants express uncertainty about how friends would react to the news. Some describe disappointment with lack of support, or difficulty trying to live a "normal" life in the face of friends' over-solicitousness. Whether and when to disclose one's antibody status to family members is a dilemma that arises whether the person's risk derives from use of intravenous drugs or sexual contact, or both, and whether or not family members are aware of that behavioral risk. Group members also find it stressful to weigh the risks and benefits of informing co-workers or a supervisor of their antibody status. Because they have tended to keep the information about their antibody status secret from all but a few others, a palpable relief and comfort emerges in the group as individual members begin to share their own experience.

Much uncertainty and distress emerges when group members anticipate the reactions of current or prospective sexual partners to disclosure of their antibody status. Some participants wished that a service existed that would notify their past partners of risk of exposure without disclosing identity of the infected contact.

Another common element in the groups has been the emergence and maintenance of hope, which seems to arise from sharing feelings, exchanging information and resources, and taking or planning to take concrete steps to change their lives. One source of hopefulness is captured by the comment that "everyone is going to die, but knowing I'm positive gives me a focus for my life." A dramatic example of change was displayed by a group member who had had only anonymous sex and had told virtually no one that he was gay; in the short span of this 3-week program he went to his first Gay Pride march, told a close heterosexual friend about his gayness (a disclosure that was well-received), and decided to tell someone he hoped to develop a relationship with that he was positive because "if he can't deal with it [my antibody status] it's his problem, not mine."

EVALUATION

Attendance during the first six cycles of the group offered in Boston has fluctuated between 5 and 16. Programs have begun in three other regions of the State where significant numbers of people have tested HIV antibody-positive.

At the start of the first and close of the last session participants complete a psychological self-report (the Symptom Check List - 90R), coded by number. They also complete a written assessment of what was most and least useful and whether the group met their expectations. At each session leaders set aside time for group members to review the progress of the group and their feelings about it.

Pre- and post-group SCL-90R indicators show wide variation within and between participants. Some manifest reduced distress; others show little change; and some show heightened distress. Often depression, anxiety and hostility decrease. Combined pre- vs. post-group measures vary similarly from group to group. These outcomes need to be evaluated further with reference to the observations of group leaders about the size, tone, and experience of the group. Results are also difficult to interpret because there is no control group with which to compare the outcomes The number and backgrounds of group participants vary, as do their baseline levels of psychological functioning. Group leaders have rotated from month to month.

Despite the fact that at the end of the third session some individuals and some groups appear as distressed or more distressed than they did at entry, group members have been remarkably uniform in affirming the value of the program. Written evaluations most often cite the support gained from making contact with other people in the same situation, for example: "When I understand that other people have similar responses I feel more accepting and willing to cope."

Many participants find information - about treatment options, medical follow-up, and community resources - valuable. Even when information is discouraging, group members seem reassured by receiving it in a setting where they can ask questions and clarify whether the confusion they experience has to do with their own lack of knowledge or the state of the art in AIDS research.

Of the few criticisms, the only consistent one is that 3 weeks is too short. Indeed, an unintended but plainly valuable outcome for some participants is the way the 3-week format introduces them to the benefits of group work for dealing with their antibody status and the feelings it elicits. It provides a kind of orientation for people with little or no prior group experience. Correspondingly, leaders of long-term support groups report that participants in this program enter their groups with a noticeably different state of mind and level of participation. Long-term behavioral risk reduction outcomes are difficult to assess, particularly because few group members acknowledge high risk practices in the months or year prior to learning their antibody status.

UNINTENDED OUTCOMES, ADAPTATIONS

The group has, unexpectedly, been important for the spouses or partners of HIV-positive members who in some cases have also come to groups. The planners of the program were concerned that people with different histories - e.g., IV drug users and gay men, or men and women - would not feel comfortable together. But experience has shown so far that the bonds of common experience seem more powerful than socio-cultural differences. Another unintended but valuable outcome is the fact that the group has served people who, having learned their antibody status over a year ago, have decided to re-examine whether to intervene more actively in maintaining their health, exploring investigational drug trials or evaluating various wellness programs. Recent reports of a more discouraging prognosis for HIV positive people than had been suggested several years ago may be rekindling these concerns. By

rotating group leadership among a variety of volunteer mental health clinicians and staff counselor-educators, the groups have also made it possible to expose a growing number of providers to the issues faced by the seropositive population and to empower them to offer treatment.

We have begun to employ this prototype to design related programs such as a 6-week program being piloted for intravenous drug users in treatment. It offers support during the decision making process prior to testing, the waiting period for results, and for a short period after members receive results. (Group leaders are sensitive to the need to validate members who decide not to seek testing.)

THE PSYCHOSOCIAL EFFECTS OF EARLY HIV IDENTIFICATION

Kenneth Hoffman, Jeanie Onitsuka, Tim Clark, Madigan Army Medical Center

Disclaimer: The views expressed in this summary are strictly those of the authors. They are not to be construed as reflecting any official opinion of the Department of Defense nor any of its subordinate commands.

Mandatory HIV screening has been performed in the military for over 2-1/2 years. Psychosocial assessments were done at Madigan on all seropositive soldiers. We analyzed our professional experiences with individual cases and reviewed records on all patients seen between June 1985 and May 1988. Of 90 military personnel, 59 (66 percent) are no longer on active duty; 19 (32 percent) of those who left were physically unable to perform their jobs. However, 37 (63 percent) who left active duty were physically capable. This presentation will review the basics of the Army HIV program and then review our analysis. The specific psychological tests discussed were performed on a selected sample but accurately reflect our impressions of the entire group.

Fort Lewis offered a unique opportunity for a psychosocial review. The hospital which did the staging was located at the work site. In other posts, patients have to travel considerable distances for staging. We not only had ready access to the patients, but also to their families, friends, and commanders. Although prepared to handle a large number of patients over 2-1/2 years, only 112 have been entered into the registry. At any given time, about 1/3 are active cases. The case management team collectively knew each patient well but key personnel have left. With the current HIV testing program and the earlier separation of those HIV+ individuals, the current HIV+ population may not be seen in such a controlled setting for some time to come.

Unfortunately, there was no planned study prior to the team's breakup. As a result, this can be best characterized as a group of case reports summarized to maintain confidentiality and individual anonymity. Information is gathered from the accumulated knowledge of team members on individuals in conjunction with a review of records for demographic information. Because of the amount of potential bias, definitive conclusions are beyond the scope of the study and information can only be used for hypotheses generation to direct further study.

The Fort Lewis AIDS Prevention Program consists of education, Army policy implementation, coordination of support services, HIV antibody testing epidemiologic follow-up on those found to be HIV+, and surveillance. The Army regulation governing the program originates with personnel, and as such, is a commander's program. Medical personnel are responsible for assisting the commander in the implementation of the program. A case management team handles all daily details and specifics on any one patient. Education has been

a particular strength of the program, however, a purely didactic educational approach ignores the emotional impact of HIV information. Theories accounting for emotional primacy in information processing help explain societal and individual "irrational" behavior.

Testing is mandated for all active duty soldiers. HIV+ troops are probably physically and certainly politically nondeployable. They can't serve as battlefield blood donors, and probably shouldn't have their immune system stressed with unusual diseases or live virus vaccines. There have been obvious ethical considerations which are difficult to resolve.

By medical regulation, the clinician has the option of initiating a medical evaluation board (MEB). Specific reasons for an HIV+ soldier would be either because of evidence of progressive clinical illness or evidence of progressive immunological deficiency. At this point, all HIV+ soldiers can be considered for an MEB. Once an MEB is initiated, it needs the concurrence of two other physicians. It is forwarded to a physical evaluation board which actually determines the extent of disability. The process usually takes 4 to 6 weeks for completion, during which time the soldier can be either a hospital inpatient or outpatient. Once initially staged, the soldier returns at least twice a year for restaging. The ultimate label resulting from the physical staging process conforms with the Walter Reed Classification System.

Prior to implementing public policy based on a test, the test should be assessed. There are specific characteristics required of a good screening test. With a high level of confidence, the Army's method for HIV testing demonstrates high sensitivity, specificity, and negative predictive value. The test is convenient and is done with little discomfort or risk. Its positive predictive value and cost is highly dependent on the prevalence in the population screened. From a military viewpoint, the benefits outweigh the risks but that may not be true for the individual. For those truly at high risk for HIV infection, testing may be unacceptable and earlier detection may be detrimental. General population interventions may reduce HIV prevalence, but need further study. For specific individuals, intervention can be useful. Our study focuses on the difficulties reported by the identified HIV+ individual. At the earlier stages of infection, the soldier can be retained on active duty but is given an indicator of medical impairment and becomes nondeployable.

For those who got a medical board while at Walter Reed Stages 1,2, and 3, the average time from initial diagnosis to start of the board is 11 months $\pm$ 6 months. Contrasting those who remained on active duty versus those who had a medical board, there were many similarities. Race was equally divided between black and white with a smaller group of hispanics. Males were predominant. The predominant military rank of HIV+ individuals was within the lower middle enlisted. The average age was 29 $\pm$ 6 years. Marital status was different. Marriage correlated with remaining on active duty while being single correlated with separation. There was no significant difference by risk group. Although not reflected as statistically significant, there was little doubt among the authors that significantly less was known about those who remained on

active duty. The testing results that follow were predominantly done on those who went to a medical board for separation.

The General Health Questionnaire and the Hopkins Symptom Checklist for anxiety and depression were administered to eight people specifically referred for evaluation. All had elevated scales. The degree of distress is remarkable. These checklists focus on the present and ask the patient to compare the present with the usual.

Along with a comprehensive neuropsychiatric test battery, the Sickness Impact Profile (SIP), the Millon Behavioral Health Inventory (MBHI), and the Beck Depression Index was given. Represented is a predominance of soldiers for medical board since the neuropsychiatric results were usually included as part of the board. Of 21 tested, 35 percent indicate moderate or severe levels of depression on Beck's somatically based index.

The Sickness Impact Profile (SIP) is a measure of the impact illness has on function; here, the HIV+ label and symptoms is considered the "sickness". Twenty-one patients were tested. Thirty-three percent indicated significant difficulties with recreation and pastimes as opposed to 14 percent with work. Forty-eight percent had difficulties with social interaction, 38 percent had difficulties with alertness behavior, 29 percent had difficulties with emotional behavior, and 19 percent difficulties with communication. Within the physical section, there are three categories. There were no overall physical difficulties. Fifty-seven percent of the tested soldiers had 1 or more elevated scores on the SIP. Social interaction difficulty is most commonly associated with the fewest difficulties. Work and communication difficulties are associated with the most difficulties.

The Millon Behavioral Health Inventory (MBHI) is a 150 item questionnaire intended for use in the assessment and management of the physically ill patient. Fourteen patients were tested. Twenty-two percent indicated feelings of chronic tension; 36 percent related feelings of recent stress. Twenty-nine percent appeared premorbidly pessimistic while 14 percent expressed future despair. Twenty-two percent expressed feeling socially alienated. No one expressed having significant somatic anxiety. Seventy-one percent of the tested soldiers had 1 or more significant MBHI scale elevations. Recent stress was associated with the fewest number of other scale elevations while social alienation was associated with the most. Chronic tension, premorbid pessimism, and future despair usually were associated with one or more other difficulties.

CONCLUSIONS

Early detection of HIV carries significant psychosocial risk for the individual and, in specific cases, may increase the risk to society in general. Should an HIV+ individual have a stress reaction, immediate intervention can help mitigate future morbidity. Chronic stress and tension leads to significant social disability, anxiety, and depression. Marriage helps retain occupational function, however, an HIV diagnosis is likely to chronically strain previous relationships resulting in social isolation. Acceptance and integration of social affect are essential for developing a consistently rational HIV public health policy.

A MODEL OF PSYCHOSOCIAL INTERVENTION IN A FAMILY PRACTICE CENTER: FOR PERSONS WITH HUMAN IMMUNODEFICIENCY VIRUS

Joyce Perkins, T.J. Woolridge, R.A. Francis; Meharry Medical College, School of Medicine, Department of Family Medicine, Nashville, Tennessee

INTRODUCTION

AIDS, the Acquired Immunodeficiency Syndrome, is an infectious disease caused by the human immunodeficiency virus (HIV). This virus suppresses the immune system and promotes infections which are not normally found in immunocompetent persons. These infections are the usual causes of death in HIV-infected patients. HIV can also infect cells in the brain and central nervous system and may cause a severe dementia. As of this writing, over 72,000 Acquired Immunodeficiency Syndrome (AIDS) cases have been diagnosed in the United States. More than 40,000 persons have died from this disease. More than 960 children under the age of thirteen have been diagnosed with AIDS.

In the U.S. over 90 percent of adults with diagnosed AIDS have been gay men, intravenous (IV) drug users, or the sex partners of IV drug users; 61 percent of pediatric cases have been children of parents who have engaged in high risk behavior (bisexual men, IV drug users, or other sexual partners). (CDC-December 29, 1986).

Over 400 cases of AIDS have been reported among residents of Tennessee, 80 percent cases are white and 20 percent are black. Out of these 400 patients, 70 percent have already died. Due to alternate testing sites the number of HIV positive patients are increasing and out of that number Drugs & IV users are a large risk factor. It is also reported that the number of cases are doubling every 10-12 months (Tennessee State Health and Environment Department). The economic impact of the disease has been staggering on both local and national levels.

In response to the unique biopsychosocial issues presented by this disease, this study reports the observation of psychosocial intervention at our Family Practice Center. The following model emphasizes the need for counseling of patients with HIV infection, AIDS Related Complex (ARC), or full-blown AIDS for communication, good clinical practice, and consistency.

ABSTRACT

The Family Practice Center (FPC) of Meharry Medical College has developed a model of psychosocial intervention for patients with AIDS and HIV-related

conditions. The Patients served by this Center are socially and economically disadvantaged with minimal social supports and limited access to medical care.

All patients diagnosed or suspected of being at high risk for AIDS are evaluated by a trained AIDS counselor using a sixteen page inventory assessment form. Individualized treatment plans are then developed to provide medical, emotional, social, and economic assistance to all patients.

Our 30 months of experience suggests that patients, their lovers, family members, and friends are under severe stress. Persons with negative antibodies but at a high risk for infection are also found to exhibit symptoms indicative of stress.

In our study group, a number of important symptoms have surfaced: denial, shock, and depression over the helplessness felt in attempting to deal with a terminal illness. Shock and denial can create confusion at a time when personal decisions are required. Fear and anxiety of death, social isolation from friends, family, and medical community, as well as sexual rejection are some of the issues faced by the patient. Anger, guilt, and frustration lead to feelings of uncertainty about the illness and effectiveness of treatments. The preoccupation with economic problems and suicidal feelings is of a major concern to patients. On evaluation, we have found that individual and group counseling greatly enhances the quality of life for these patients and augments the effectiveness of medical management and actually decreases the cost of medical care.

METHOD

Since 1985, the Family Practice Center at Meharry Medical College has actively provided the medical and psychosocial services to AIDS patients.

Upon confirmation of a diagnosis of HIV seropositivity, these patients are then referred to our center by local health agencies (Nashville CARES, Meharry Alcohol & Drug Abuse Programs, Out of County Physicians, High Risk Populations). The center also receives a number of patients who are aware that they are in a high risk group and wish to be tested.

The patients are then enrolled in the center for management. All patients fill out a questionnaire related to family background, drug and alcohol history, and a detailed sexual history.

Patients with positive HIV antibodies, ARC or full-blown AIDS are followed by an attending physician, resident, counselor and a nurse. Other consultants are often brought in on the case if the evaluation deems it necessary.

Lab tests include CBC with differential, platelet count, and a measure of the current immunological status, which consists of absolute lymphocyte count, flow

cytometry for T-lymphocyte subsets with T4/T8 ratio, and immunoelectrophoresis. These studies are obtained on all patients who are seropositive.

DISCUSSION

Patients managed at our center are more likely to be unemployed or working for minimal wages, and therefore do not have medical coverage. Many of these patients need assistance for their expensive medication. Meharry Family Practice Center have limited disposable funds. Several churches have come forward to promote limited financial assistance. Despite the availability of financial funds, more funding is necessary in order to continue with this work.

Further complicating the issue, drug and alcohol treatment centers have not designated counselors to assist in the AIDS counseling and AIDS education for their clients. The implication is that these patients are not reaching health care.

Although the Center has had to work with a number of limitations such as a lack of financial support, few black counselors, and limited educational materials, we consider the program a success and a step forward because most patients are readily accepting medical and counseling services.

The medical and psychosocial care of patients infected with HIV is a problem involving a complex, multi-system disease and multiple hospitalizations. Hospitals are strained by the inadequate financial and social resources and by the fear of the contagious nature of this condition.

The uniqueness of our Family Practice Center is its ability and willingness to provide comprehensive and cost effective care to AIDS patients, regardless of their ability to pay.

RECOMMENDATION

This writer recommends that the following measures be adopted in planning for the provision of effective psychosocial interventions.

1. Development and expansion of Federal, State and local policy for medical indigent care funding.

2. Local Health Departments should expand their social, medical, and counseling services for patients with HIV seropositivity, ARC, and AIDS.

3. The need for Federal, State and city monies for education, social services and medical research in the area of AIDS.

4. There should be Federal, State and county housing available for people with ARC and AIDS who do not have other housing alternatives.

5. Outreach efforts should be directed toward the adolescent population due to the fact that many adolescents are experimenting with drugs and their sexuality. We recommend that AIDS education be a part of the regular health education curricula.

6. The creation of outpatient AIDS clinics

7. Educational material and strategies should be developed that are culturally sensitive and specific to each community.

8. Criteria should be developed to fund "family assistant programs" for people with AIDS.

9. Provide education for counselors/social workers to re-evaluate their values and attitudes towards working with IV drug abusers, homosexuals, and people in need.

AIDS Challenges for Health Care Workers

AIDS AND THE HOSPITAL HEALTH CARE WORKER

Judith Cooksey, Joan Dworkin, Gary Albrecht, University of Illinois at Chicago, Chicago, Illinois

One of the challenges of the AIDS epidemic is to have an adequate supply of health care services and providers. Health care workers (HCW) must be trained in patient management and be prepared to deal with the issues raised by the epidemic. In order to plan appropriate training and education programs for HCW, educators must take into account the HCW's own concerns and attitudes about AIDS.

This study was undertaken to assess the knowledge, attitudes and concerns of HCW from all occupational backgrounds at a large university hospital in Chicago. In 1987 Chicago ranked 8th in the number of cases of AIDS among the metropolitan areas of the U.S., however actual experience with AIDS patients had been modest with only 15 hospitals admitting more than 5 patients. The University of Illinois Hospital admitted 33 newly diagnosed AIDS patients during 1987.

METHODS

The study was conducted using an anonymous self-administered questionnaire that was distributed to hospital and clinic staff at the University of Illinois Hospital in September and October 1987. Nonprofessional staff were asked to answer the questionnaire at the beginning of a one and one-half hour educational program. Trained staff were available to answer any questions during this time. Questionnaires were distributed to professional employees by their supervisors; they were asked to complete the questionnaire and return it within 1 week.

No efforts were made to reach employees who did not attend educational programs during the survey period or who did not have the questionnaire distributed by supervisors. The questionnaire had 15 questions (91 items) on AIDS-related knowledge, experience, behavior, risk perception, attitudes, personal sociodemographic characteristics, and job experience.

RESULTS

Of 2,123 employees with patient contact, 1,492 were asked to complete questionnaires; 1,140 questionnaires were received and 1,099 were analyzed (RR = 52 percent total employees and 74 percent of those asked to respond). For purposes of analysis each HCW was classified into one of six occupational groups: four professional categories (nurses, physicians, technicians/therapists, and other professional) and two nonprofessional categories (clerical staff and support staff). Seventy-two percent of the respondents were professional staff

(35 percent nurses, 12 percent physicians, 14 percent technicians/therapists, 11 percent other professional) and 28 percent were nonprofessional staff (14 percent clerical and 14 percent support staff). The sociodemographic characteristics, job experience, and AIDS experience of the professional, nonprofessional, and total sample are listed on Table 1.

EXPERIENCE WITH AIDS PATIENTS

Sixty-four percent of the respondents had contact with at least one AIDS patient but only 27 percent had contact with five or more patients. Contact with an AIDS patient was more common among professional staff (PS) (74 percent) than nonprofessional staff (NPS) (34 percent). Professional staff also had contact with a larger number of patients with AIDS. The level of contact with patients varied by occupation. Fifty-eight percent (71 percent PS, 27 percent NPS) had talked to an AIDS patient, 46 percent (61 percent PS, 8 percent NPS) had touched a patient while providing care, and 26 percent (36 percent PS, 1 percent NPS) had performed blood tests for an AIDS patient.

When asked to describe how they felt while providing services to patients, 83 percent felt comfortable with talking to patients, 65 percent with touching patients, and only 28 percent with performing a blood test. As will be shown below, the comfort levels relate to the perceived risk of performing various services.

KNOWLEDGE

When asked how much they knew about AIDS, 16 percent responded a lot, 58 percent a moderate amount, 23 percent a little, and 3 percent nothing. More than 90 percent had received AIDS information from television and newspapers/magazines, 70 percent from professional journals, 60 percent talking to family and friends, 77 percent talking to people at work, and 52 percent lectures or inservice programs. All of the above sources were considered reliable by 90 percent of the respondents except talking with family and friends (54 percent) and talking to people at work (81 percent). There were 10 true/false questions on general AIDS knowledge; 95 percent of professionals and 69 percent of non professionals (89 percent overall) answered 8 or more correctly.

RISK PERCEPTION

When asked about their own chance of getting AIDS from their work, only 9 percent felt there was no chance (11 percent strong chance, 40 percent moderate chance, 39 percent little chance). When asked about the risk of getting AIDS by performing certain services for patients, respondents generally indicated higher risk levels with more invasive procedures. When asked to rate the level of risk, 60 percent rated talking to patients as no risk (1 percent rated high risk), 22 percent rated touching patients as no risk (8 percent rated high

risk) and 6 percent rated performing a blood test as no risk (26 percent rated high risk). Eighty-one percent felt they could reduce their own chance of getting AIDS from work and listed the following: wearing gloves, following hospital guidelines and procedures, washing hands and objects.

BEHAVIOR

Seventy-eight percent of HCW report they have changed their behavior due to AIDS. Sixty-four percent are more careful with all patients; 76 percent with AIDS contact are more careful with AIDS patients. Eighteen percent report that they have tried to avoid AIDS patients. Many report worrying about AIDS, 45 percent worry about getting infections from patients, and 30 percent worry about spreading AIDS to their own families. Thirteen percent have thought about changing jobs due to AIDS.

BELIEFS AND ATTITUDES

Respondents were asked to state whether they agreed or disagreed on a four point scale (strongly agree, agree, disagree, strongly disagree) to several statements on beliefs and attitudes about AIDS, patient care, and personal health. Responses are listed in Table 2.

CONCLUSIONS

Although experience with AIDS patients had been of limited scope at this hospital at the time of survey, concerns about AIDS were found among all occupations of HCW. HCW worry about their own risk of getting AIDS and about spreading AIDS to their family. The perceived risk of getting AIDS from work contributed to the lack of comfort in performing services for AIDS patients. Also contributing is the difficulty 20 percent of professional and 30 percent of nonprofessional staff experience with caring for patients with conditions that often coexist with AIDS (terminal illness, homosexuality, and IV drug abuse).

Health care workers have changed their behavior due to AIDS and believe they can reduce their risk of getting AIDS by taking precautions similar to those recommended by the CDC. Most believe that they have an obligation to treat all patients assigned to them and only a small minority have avoided AIDS patients. They feel patients with AIDS should be treated on a special AIDS unit yet are reluctant to consider working on such a special unit.

IMPLICATIONS FOR EDUCATION PROGRAMS

Health care workers are concerned about AIDS and generally consider information reliable. Therefore, hospital-wide programs should be established to provide AIDS information. They believe they can reduce their chance of AIDS exposure, by taking precautions, therefore programs should provide clear guidelines on proper precautions and techniques. The level of worry about

AIDS among HCW is high and found in all occupations and this should be discussed openly to allow individuals to deal with their concerns. Although not specifically addressed by our study it may be useful to consider developing support programs in addition to education programs for HCW.

TABLE 1

Sociodemographic Characteristics and Experience of HCW

	Professional	Nonprofessional	Total
Sample Size	791 (72%)	308 (28%)	1,099
Age (Median)	30 yrs	34 yrs	31 yrs
Female	73%	76%	74%
Education			
High school or less	2%	39%	12%
College/technical school (1-2 years)	11%	37%	19%
College/technical school (3-4 years)	44%	20%	38%
Graduate School	42%	3%	31%
Race			
Black	15%	66%	29%
Caucasian	69%	11%	53%
Hispanic	3%	14%	6%
Oriental	9%	3%	7%
Other	3%	5%	4%
Years worked in a hospital	7yrs	7.5yrs	7yrs
AIDS Experience			
No Contact	24%	67%	36%
Contact	76%	33%	64%
5 or more patients	35%	27%	33%
Non-invasive contact	31%	32%	31%
Invasive contact	45%	1%	32%

TABLE 2
Beliefs and Attitudes
(Percent respondents who agree with each statement)

	Professional	Nonprofessional	Significance (x^2:p<.001)
Health workers have an obligation to provide care to each patient assigned to them	80%	67%	S
Patients with AIDS should be treated in a special AIDS unit	68%	67%	NS
I would continue working with a coworker who carried the AIDS virus if the coworker was careful	44%	58%	S
Health workers should be informed when they treat a patient with AIDS	47%	61%	S
I can reduce my risk of getting AIDS by following safety and infection control guidelines	89%	56%	S
I worry about getting infection from patients.	71%	74%	NS
I worry a lot about treating AIDS patients	77%	68%	S
My family is concerned about my contact with AIDS patients	53%	65%	S
I find it difficult to care for terminally ill patients	21%	32%	S
I find it difficult to care for male homosexuals	17%	31%	S
I find it difficult to care for IV drug abusers	23%	33%	S
I would be willing to work on an AIDS unit	18%	21%	NS

AIDS PATIENTS AND SOCIAL WORKERS: THE RELATIONSHIP BETWEEN BURNOUT, PHYSICAL SYMPTOMOLOGY AND POTENCY

Marcie Egan, School of Social Work, University of Maryland, Baltimore, Maryland

The AIDS epidemic and its present and potential impact on the healthcare delivery system as an institution promote a plethora of societal, organizational and individual, as well as political and economic, dilemmas and controversies. The intent of the present research, however, was to examine one small piece of that larger fabric. The AIDS epidemic may well present a particularly stressful area of healthcare-medical social work practice for the worker. The research herein reported focused upon the impact on the social worker of providing services to PWAs (Persons with AIDS) within the hospital setting. Wiener and Furstenberg both note that this group of clients, whose numbers are burgeoning, have acute psychosocial needs (1). These psychosocial needs may include the impact of having AIDS and its medical crises/sequelae, the responses of the patient's family, friends, employers and, thereby, various ramifications on his/her social and family supports, lifestyle, finances, housing, and medical insurance.

Such acuity and multiplicity of needs in a stigmatized, terminally ill client population are, plausibly, the client characteristics that are psychologically stressful to healthcare social workers. It has been postulated that such work leads to burnout because it requires workers to interact in intense and psychologically intimate ways with clients and patients who are in acute and/or chronic states of neediness.

In many areas the worker may also have few available resources for successful problem resolution or traditional types of assistance. Additionally, this "specialty" worker may be isolated within the healthcare setting or lack collegial/team backup and support. The patient characteristics of acute or terminal illness, neediness, stigmatization, emaciation, and suffering have been shown as related to worker stress and burnout in other healthcare areas. Work characteristics of isolation, caseload size and composition are also known to be associated with stress and burnout (2). How these are related in specific types of health care social work is less well documented. Social work with AIDS patients provides a defined area of social work practice which may be highly stressful and potentially one of burnout.

Stress and burnout have been found to be effected by or correlated with several variables including worker autonomy, team versus individual-focused organization, length of time in such work, variety of caseload, and social supports. The worker's own personality/psychological characteristics have

received less attention. Work stress and burnout have been found to correlate with physical stress symptoms and illnesses (3).

Research in Israel has found that confidence in self and a belief that society is just and fair are closely linked to health and emotional homeostasis. Those characteristics have been conceptualized by Ben Sira as "potency" and defined as:

> ...a person's enduring confidence in his own capacities as well as confidence in and commitment to his/her environment, which is perceived as being characterized by a basically meaningful and predictable order and by a reliable and just distribution of rewards (4).

The experience of workers with PWAs has been only minimally studied. Anecdotal reports about that experience are, as noted, occurring more frequently as the extent of the epidemic and its effects become more widely known and understood. The specific impact on professionals of this healthcare area was examined to gain knowledge upon which to design and develop empirically-based interventions and training programs for a group of healthcare professionals who will become increasingly needed in the very near future.

In summary, social work with AIDS patients combines the elements reported in the literature to be stressful for healthcare social workers. Service provision to this population involves interactions with patients who are terminally and acutely ill, in recurrent crises, psycho-socially needy and problem-plagued. It was proposed that confidence in one's self and in one's society would be negatively related to emotional exhaustion, a desire to distance one's self from patients and physical stress-related symptoms. It was also postulated that such beliefs about self and society should be positively correlated to a sense of work-related accomplishment.

METHODOLOGY

Design/Sample

The relationship(s) between burnout, potency, and stress symptomology were examined through a survey mailed to social workers who provide services to AIDS patients in hospital settings. The sample of social workers (N=101) was obtained through direct inquiry to directors of social work departments in eligible hospitals in the 10 States of highest AIDS incidence and the District of Columbia.

The resultant sample was purposive only and does not, of course, provide representativeness for external generalization to all AIDS patients' social workers. Respondents completed a 14-page questionnaire which was a self-

administered compilation of items and scales. The Maslach Burnout Inventory and Ben Sira's Potency Scale were included as well as a Symptom Checklist.

Data Analyses

Analyses of demographic data provide a picture of the "average" social worker in the study as being MSW-degreed, female, in a committed relationship, white, 38.7 years old, with 10.13 years in social work and 2.7 years specifically in social work with PWAs. Examining differences between racial and gender groups by years in social work/PWAs resulted in t-test significance levels (t=p.02;f=6.01,p.002) between whites and non-whites in years of PWA/Social Work and no difference between gender groups. No statistically significant relationships between other demographic characteristics and main variables were revealed.

Analysis of Main Variables

The main variables (burnout, potency, and stress symptoms) were analyzed. Means and standard deviations of the variables are depicted in Table 1.

Correlational Analysis

Initial correlational analyses supported the hypothesized negative relationships between emotional exhaustion, depersonalization, and potency and the positive relationship between personal accomplishment and potency. The Symptom Checklist was correlated to the burnout measures and potency in the hypothesized directions as well. The model depicts the hypothesized relationship between Potency and the outcome variables and the correlation coefficients obtained.

Implications

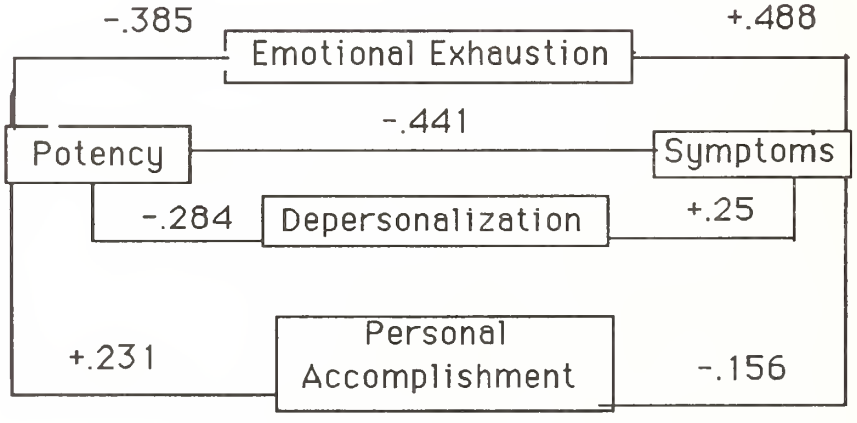
The hypothesized relationships were marginally substantiated by the research. The belief system about self and society of the worker was found to be correlated with burnout subscales and stress symptoms checklist. Just as relevant was the finding that worker burnout did not correlate as highly with the other variables often cited as associated. Among these variables were: worker isolation, years in social work or social work with PWAs, social/familial support, organizational structure, size or composition of caseload, worker autonomy, or participation in AIDs' worker support group. These findings suggest further research comparing other groups of social workers with workers of this specialty

area. Research is also warranted examining potency as a basis for intervention on burnout. That is, is potency capable of preventing or intervening in the experience of work related stress and burnout? Can it be implemented in recruitment, training, and in-service education to intervene in burnout prone areas of practice?

Table I

Means, Range and Standard Deviations of Major Variables

Variable	Mean	Range	Standard Deviation
Potency	59.40	39-72	7.14
Emotional Exhaustion	30.86	9-55	8.95
Personal Accomplishment	47.06	26-56	6.73
Depersonalization	11.60	5-26	5.62
Symptoms	18.56	10-31	4.06



References

1. Lori Wiener, "The Role of the Social Worker with AIDS Patients," Public Welfare, Fall, 1986, pp. 38-41; Anne-Linda Furstenberg, "Social Work and AIDS," Social Work in Health Care 9 (4), Summer, 1984, pp. 45-62.

2. Christine Maslach, "Burned-Out Cops and their Families," Psychology Today, 12(2), 1979, pp. 59-62; Christine Maslach and Susan Jackson, "The Measurement of Experienced Burnout," Journal of Occupational Behavior 2, 1981, pp. 99-113; Christine Maslach and Susan Jackson, "The Burnout Syndrome in the Health Professions," in Social Psychology of Health and Illness, (Eds.) G. Sanders & J. Sulo, Hillsdale, NJ: Lawrence Erlbaum, 1982. David Himle, Srinika Jayaratne and Wayne Chess, "Gender Differences in Work Stress Among Clinical Social Workers," Journal of Social Service Review 10 (1), pp. 41-56. William C. Sze and Barry Ivker, "Stress in Social Workers: The Impact of Setting and Role," Social Casework, March, 1986, pp. 141-148. Kay Davidson, "Social Work with Cancer Patients," Social Work in Health Care 10 (4), 1985, pp. 73-82. Barry Farber (Ed.) Stress and Burnout in Human Service Professions, New York, Pergamon Press, 1983; Thomas Muldary, Burnout and Health Professionals, Norwalk, Conn.: 1983; William Paine (Ed.) Job Stress and Burnout, Beverly Hills, Calif.: Sage Publications, 1982.

3. Robert Caplan, S. Cobb, J. French, R. Van Harrison and S. Pinneau. Job Demands and Worker Health, Health, Education and Welfare Publication, Washington, D.C., 1975; Thomas W. Muldary, Burnout and Health Professionals Norwalk, Connecticut, 1983; William Paine (Ed.) Job Stress and Burnout, Beverly Hills, Sage Publications, 1982.

4. Zeev Ben-Sira, "Potency: A Stress-Buffering Link in the Coping-Stress-Disease Relationship," Social Science and Medicine 21 (4), 1985, pp. 397-406; "The Structure of Readjustment of the Disabled: An Additional Perspective on Rehabilitation," Social Science and Medicine, 15A, 1981, pp. 565-580; Zeev Ben-Sira, "Chronic Illness, Stress and Coping," Social Science and Medicine 18 (9), 1984, pp. 725-736; "Loss, Stress and Readjustment: The Structure of Coping with Bereavement and Disability," Social Science Medicine 17, 1983, pp. 1619-1632.

AIDS AND DENTISTRY: WHAT DOES THE PUBLIC THINK?

Barbara Gerbert, Bryan Maguire, and Sherry Spitzer; University of California, San Francisco

(This study was supported by a grant from the AIDS Clinical Research Center, University of California, San Francisco.)

As the AIDS health crisis continues, the need becomes more urgent for all health care professionals to care for people with AIDS and HIV infection. In dentistry, however, as in other areas of health care, these patients do not always have access to care. Infection control, another issue of importance with regard to HIV infection, is not practiced rigorously by dentists.

Some dentists are simply refusing to care for AIDS patients (1,2). Others express reluctance to provide such care. In a 1986 survey of dentists in California, 63 percent said they did not want to accept as patients those in the high-risk groups, and 74 percent said they would rather refer people at risk for AIDS or people with AIDS/ARC to other dental professionals (3). This same survey showed that dentists are not using adequate infection control. None of the respondents used all 14 procedures designated as "essential" by the Centers for Disease Control for controlling the spread of infection, and only 58 percent reported changing gloves between patients (3).

The fear of frightening patients away from a practice underlies, at least in part, many dentists' reluctance to use infection control and their desire to avoid treating patients with AIDS or HIV infection in their practices. many dentists assume that the use of barrier products (e.g., masks, protective eyewear) will cause their patients to feel a greater sense of risk for HIV infection. In the survey noted above, 85 percent of respondents said they believed that if they were to treat patients with AIDS or ARC, other patients would be reluctant to continue in their care (3).

It appears, then, that dentists are limiting access to care and are reluctant to use infection control measures because of what they perceive to be the public's attitudes toward AIDS in the contest of dentistry. The public's attitudes about AIDS in general do reflect misconceptions about casual transmission. For instance, 39 percent of adults surveyed nationwide thought the AIDS virus could be transmitted by sharing eating utensils with an infected person (4). Whether such misconceptions extend to the dental office is the subject of this study.

METHODS

Four focus groups, each composed of 9-12 participants, were conducted in May 1988. To compare the attitudes of people living in areas of high AIDS prevalence withthose of people living where AIDS is less common, two groups were held in San Francisco and two were held in Bakersfield, California. The authors designed the study in collaboration with a professional market research firm, Communication Technologies, Inc. (CTI), which has extensive experience in conducting AIDS and focus-group research.

Subjects were recruited by a trained professional at CTI using random-digit dialing. An incentive fee was offered in exchange for participation in a focus group ($35 in San Francisco, $25 in Bakersfield). Subjects were included only if they had visited a dentist within the past 5 years, were 18 years of age or older, and spoke and understood English.

Upon arriving at the focus group site, subjects gave written consent for their participation in the study. The group facilitator (an experienced professional from CTI) then began the 1.5-2 hour discussion period with a series of open-ended questions. Four content areas were identified for coverage: (1) concern about contagion and transmission of the AIDS virus in the dental office; (2) reactions to infection control procedures; (3) level of knowledge about AIDS and HIV; and (4) communication with dentists about these issues. The facilitator's task was to guide the discussion toward these topic areas but to avoid directly introducing concepts as much as possible

Each focus group session was recorded on videotape or audiotape and observed by a member of the research team. Recordings were later reviewed and analyzed.

RESULTS

Approximately half of the participants were male. About two participants in each group were non-Caucasian. The age of participants ranged from 20-75 years, and yearly household income ranged from less than $15,000 to more than $75,000

Concern About Contracting or Transmitting AIDS in the Dental Setting. Most participants had no concerns about contracting any disease from their dentist. Almost no one had given any thought to whether they might contract AIDS from their dentist, and most had difficulty imagining a scenario where this might take place.

When participants considered how they would react to being treated by a dentist who had treated someone with AIDS, many in Bakersfield said they would be uncomfortable and might look for another dentist. Some participants in Bakersfield favored separate dental-care facilities or rooms for people with AIDS. In San Francisco, many participants simply assumed their dentist treated people with AIDS, and thought that it made no difference where people with AIDS were treated as long as proper infection control procedures were followed.

Reactions to Infection Control Procedures. The participants' level of comfort with infection control procedures was extremely high. Not one participant in either location felt at all threatened or uncomfortable with any of the infection control measures used by their dentist. In fact, many preferred that these procedures be in place. Some felt that a dentist's use of a procedure they could see (such as wearing gloves) indicated they were also using less visible measures.

Some admitted feeling concerned when they first saw their dentist wearing gloves or a mask. One woman said her first reaction was, "He doesn't trust me:" but then she realized, and most others agreed, "...he has to deal with everybody."

Knowledge about AIDS. Most participants in both cities were very knowledgeable about the ways that the AIDS virus is transmitted through sexual intercourse, through sharing of needles, from mother to child, and from blood transfusions. In Bakersfield, however, there was considerably more confusion about possible casual routes of transmission, with several participants convinced that the disease was transmitted casually.

Communication with Dentists About AIDS and Infection Control Procedures. Few of the participants in either city had discussed AIDS or infection control with their dental providers. Some had made passing reference to the appearance of new infection control strategies, such as, "Hey, I notice you're wearing these things now." Most, however, said nothing, and simply assumed new procedures had been put into place to control the spread of disease.

Most participants said they would be uncomfortable talking about these issues with their dentist and didn't see the need for such discussions. There was a similar response to the idea of being assessed for AIDS by any health professional; most could see the usefulness of this practice, but indicated they might be uncomfortable.

DISCUSSION

The focus group discussions revealed that none of the participants in either group feared transmission of diseases such as AIDS in the dental office. This was probably due, at least in part, to participants' high level of knowledge about

AIDS and the routes of HIV transmission. A number of those from Bakersfield, however, where cases of AIDS are less common, did not want to be treated by a dentist who had treated someone with AIDS, and many in that group favored separate facilities or treatment rooms for people with AIDS or HIV infection.

Why, if the Bakersfield participants did not fear infection, did they want to avoid practices where AIDS patients were being treated? We believe they were expressing a generalized fear of AIDS, or "AIDS phobia." Based on the assumption that some patients may have an irrational fear of AIDS, dentists should be careful to protect the confidentiality of any patients in their practice who have AIDS or who identify themselves as seropositive for HIV.

One of the strongest findings of the focus group discussions was the participants' acceptance, and even appreciation, of rigorous infection control. The use of visible precautions to avoid transmission inspired patients' confidence that less observable measures were being taken as well. If these attitudes are typical of most dental patients, dentists can assume that their use of infection control will not frighten patients into seeking care elsewhere.

Another implication for practice can be found in the participants' reluctance to discuss issues concerning AIDS with their dentist. No one expressed a desire for such communication, and most said it would make them uncomfortable. Dentists can expect that, unless treatment issues require that AIDS be discussed, introduction of the topic would best be left to the patient.

The findings from this study suggest that dental patients are knowledgeable about AIDS and are not afraid of contracting the disease in the dental setting. Moreover, they welcome the use of infection control procedures. Dentists need not fear that the inclusion of AIDS or HIV-infected patients in their practices or the use of infection control measures will frighten patients into seeking care elsewhere.

References

1. Raber, PE. AIDS: Prevent its spread, treat its victims. Dentistry Today 4:1,21, 1985.

2. Hartley, M. Dental discrimination? AIDS victim challenges treatment refusal. Dentist, May-June: 1,24, 1988.

3. Gerbert, B. AIDS and infection control in dental practice: Dentists' attitudes, knowledge, and behavior. Journal of the American Dental Association 114:311-314, 1987.

4. National Center for Health Statistics, AIDS Knowledge and Attitudes for December 1987, Provisional Data from National Health Interview Survey, Advance Data from Vital and Health Statistics, by D.A. Dawson and O.T. Thornberry, DHHS Publication No. 88-1250 (Hyattsville, Maryland: Public Health Service, 1988).

STRESS AND BURNOUT IN THE AIDS HEALTH CARE WORKER

Donna L. Higgins and Deborah Rugg, Division of Sexually Transmitted Disease, Centers for Prevention Services, Centers for Disease Control, Atlanta, Georgia

The escalating prevention and treatment demands placed on the health care system in this country by the AIDS epidemic are frequently translated into overwhelming problems for the individual health professional. Those directly involved in providing HIV prevention or treatment services - be it the prevention of HIV counseling and antibody testing, or treating HIV infection - are exposed to a series of challenging circumstances ("stressors") that can induce feelings of stress. Client overload, facility understaffing, and issues of death and dying are all common problems faced by AIDS health care workers. While there is existing literature describing the impact of AIDS on health care workers (Abrams, D., 1988; Bor and Miller, 1988; Rugg, 1988), the information is limited. This paper will provide a brief overview of the issues of stress and burnout in AIDS health care workers by examining three areas. The first is empirical data regarding the level of stress in counselors at HIV counseling and testing sites (CTS). Secondly, we will review signs and symptoms of stress and burnout in health care workers in general, and specifically those problems unique to those working in the field of AIDS. Lastly, we will review methods of coping with AIDS-related burnout.

In July 1987, a survey of counselors working at 54 California HIV counseling and testing sites was conducted by Rugg, Fagan, and Rhodes (1988). This survey focused on numerous HIV counselor characteristics such as levels of stress, AIDS knowledge and attitudes, job-related practices, job choice, social support, and demographics. Those results reflecting the counselors' level of stress and burnout are of particular interest here; the demographic information allows one to compare the respondents of this study to his/her own work environment and experiences.

The majority of the CTS counselors in this study were white heterosexual females with an average age of 40. Minority counselors were represented in the same proportions as minority clients. These counselors were highly educated and had specific CTS counselor training. Many held another job in a health-related field and most had been or were public health nurses.

Twenty-two percent of the respondents reported having difficulty in discussing AIDS or sexual issues. Specifically, those clients who were angry, hostile, or displayed a "know it all" attitude were reported to be difficult to counsel. Additionally, those clients who were culturally different from the counselor and those who were prone to deny their risk were also likely to be labeled as challenging clients.

A correlation was found to exist between reported counselor stress and how much support they perceived they were getting from their superiors. Those counselors who reported moderate to high levels of stress were significantly less likely to have perceived support from their administrator; in addition, these counselors indicated that they had little choice in being designated as a CTS counselor.

Twenty-seven percent of the respondents suggested ideas to decrease job stress. These included: more staff, particularly counselors; more time for each counseling session; and more frequent HIV updates, perhaps in the form of in-service presentations. Rugg et al. (1988) recommended several ideas as a result of this survey for the improvement of HIV counseling and testing as well as methods to reduce counselor stress and potential burnout. Among these suggestions were: (1) provide role-playing vignettes and practice for those counselors who feel uncomfortable in certain counseling situations; (2) training for administrators to enable them to be supportive of their counselors and then evaluated on their efforts; (3) examine critically the length of pre- and post-test counseling sessions and determine if more time is needed; and hire more staff if necessary.

From this study, it appears that most CTS counselors are coping adequately with the stress of their jobs. However, it must be noted that one quarter of the staff indicated feeling moderate to high levels of stress, and it is likely that more counselors were feeling stressed, yet did not report it. Denial on one's level of stress can be an effective means of short-term coping. With this indication that many HIV CTS counselors are feeling stressed and are burnout candidates, we turn now to a discussion of the meaning of stress and burnout and their signs and symptoms in AIDS health care workers.

Stress can be defined as any event in which environmental or internal demands tax or exceed the adaptive resources of an individual, social system, or tissue system (Lazarus, 1966). We experience stress regularly. Stress, such as that experienced when falling in love, may be pleasant. Selye (1976) calls this type of stress "eustress." That stress which is unpleasant and feels overbearing is designated "distress" (1976). However, it is not eustress or distress which leads to problems on the job but rather the ability to cope with stress. When one fails to cope with stress on the job, the result can be burnout, a significant loss of interest, motivation, energy, satisfaction, and effectiveness in connection with one's work (Lazarus, 1966).

The types of stressors to which an AIDS health care worker is exposed depends on the stage of HIV health care with which he/she is involved. For example, a CTS counselor deals with people who are learning their serostatus. The pre- and post-test counseling sessions involve varying degrees of stress, and the clinician must counsel people from differing cultural, ethnic, and sexual preference backgrounds, all of which have been reported by a significant minority as stressful by Rugg et al.'s study. The clinician is faced with disclosing a person's serostatus, relaying information concerning safe sex practices, follow-up medical care (if seropositive), and counseling that person during a

period of great relief or utter despair. Some counselors report feeling uncomfortable providing explicit information on sexual practices while others report feeling discomfort telling a person she/he is seropositive. Finally, the health care worker at this stage is unsure if he/she is having any impact whatsoever on the client's ability to follow recommendations regarding safer practices and the notification of partners if seropositive.

The AIDS health care worker is prone to those stressors which affect all health care workers. Examples are patient overload, insufficient resources, work pressure, dealing with others who are burned out, working with families, and tending to another person's psychological and physiological status. Those caring for the terminally ill, such as the hospice worker, are faced with added stressors: psychologically and physiologically supporting the dying person, lending support to the significant others of the dying person, watching the deterioration of the patient's physiological and, often, psychological state, and the exposure to repetitive deaths. Working so closely with death and dying requires a person to consider his/her own mortality; this self-examination is stressful in its own right.

The added dimension of dealing with patients who have developed ARC or AIDS compounds the stressors. The AIDS health care worker is confronted with young people dying prematurely. Often the patient is a homosexual and the health care worker may be faced with feelings of homophobia, or at least confronted with how they feel about homosexuality. One may fear contagion and mortality and may even be ostracized from their family, friends, and neighbors due to their own fears of HIV. Furthermore, the AIDS health care worker may feel inept due to the inability to reassure patients in a field where there is much uncertainty.

These are the types of stressors facing AIDS health care workers. If effective coping strategies aren't built into the clinician's lifestyle, the effects of stress in his/her life will become evident. Stress can manifest itself in physical and or psychological ways. For example, depression with symptoms such as low energy level, crying spells, increased sleep, and a decreased sex drive is a common manifestation of burnout. Frequently our body takes on the stress in more descriptive ways such as headaches (tension and migraine), shoulder tension, lower back pain, and PMS if the health care worker is a woman. One may be anxious and suffer from insomnia, "jumpiness", and a free-floating type anxiety. An effective indicator is a person's cynicism and criticalness of the system, clients, peers, etc. Furthermore, one may have a short temper and take out stress on significant others at home, at which time relationship problems may appear and further add to the person's level of stress.

If a person is suffering from burnout there are numerous techniques and skills which will lessen the above symptoms. An individualized program which includes relaxation, exercise, and nutrition will greatly reduce the effects of burnout. Techniques of relaxation include breathing techniques, meditation, and creative visualization; instructional classes and books on these techniques are available in most areas. A regular program of exercise (consult physician

first) is also an effective way to cope with stress. Proper nutrition is necessary to prevent fatigue and other symptoms of stressful situations. Finally, the AIDS health care worker may wish to consider individual psychotherapy for him/herself. It is inherent in a field which is filled with so many meaningful human interactions that one is faced with his/her own feelings and the desire to make changes. Individual psychotherapy provides a safe place to do this.

Stress-reducing techniques which can be incorporated into the life of the health care system itself include the following: weekly staff support groups or "gripe sessions" to allow health care workers to ventilate their feelings of frustration, anger, hopelessness, or even relate moments of happiness, joy, etc. Professional facilitation of these meetings and supervision by a licensed psychotherapist will help the staff discuss their feelings and to know their limits in talking with clients about the client's problems. This is also an opportunity to provide the staff with a list of appropriate psychotherapy referrals for the client. Built in "mental health days" provide the staff with time off to relax and help reduce the symptoms of burnout. The provision of frequent in-services on HIV and methods of stress reduction are useful. A staff retreat is an opportunity to incorporate all of these stress reducing methods. Lastly, a job rotation program in which frontline HIV counselors and caregivers can get a perspective on their work is effective. An example of this is a CTS counselor giving public talks on HIV information and their experiences as an AIDS health care giver or rotating jobs with other AIDS-related staff members.

It is evident that there is no immediate relief in sight for those dealing with this epidemic. These stressors are likely to remain a part of the health care providers' lives. It is imperative that this is acknowledged now and methods of coping are built into the individual health care provider's life and also into the health care system itself.

References

1. Abrams, D. Burnout. Paper presented at the Fourth International Conference on AIDS, Stockholm, Sweden, June 1988.

2. Bor, R., and Miller, R. Managing staff stress from working with patients with AIDS/HIV. Paper presented at the Fourth International Conference on AIDS, Stockholm, Sweden, June 1988.

3. Lazarus, R.S., Psychological stress and the coping process. New York: McGraw-Hill, 1966.

4. Rugg, D., Fagan, R., Rhodes, F. An evaluation of public health AIDS counselors: Their job-related stress, knowledge, attitudes and behavior. Centers for Disease Control and the Association of Schools of Public Health by cooperative agreement. Manuscript in preparation, 1988.

5. Selye, H. The stress of life. New York: McGraw-Hill, 1976.

AIDS Education for Health Professionals

TEACHING AIDS IN MEDICAL SCHOOL CURRICULAR ISSUES AND STRATEGIES

Francois E. Alouf, Associate Professor of Psychiatry and Behavioral Sciences; Director of Medical Student Education, Northwestern University Medical School, Chicago, Illinois.

THE ISSUES

AIDS is a major national and international public health concern. The Centers for Disease Control estimates that 1 to 1.5 million people in this country are HIV positive and that by 1991 we will have 270,000 cumulative cases of AIDS (1). Furthermore, as of now we have no vaccine, no cure, and a morbidity rate that approaches 100 percent. Because of its etiology, its transmission, and its immense impact on patients, their families, and society in general, the AIDS syndrome has raised far-reaching medical, legal, ethical, and public policy issues.

A growing number of surveys and research reports indicate that medical students' (and other health care professionals') concerns about caring for patients with AIDS are very complex.

In a recently published communication, Whalen (2) refers to the case of a junior medicine clerkship student who, when assigned to perform the requisite medical and laboratory work-up on an AIDS patient, refused to draw blood. The student claimed he had not "been adequately educated regarding the possibility of transmission of the AIDS virus" and had not been "schooled in the precautions to be taken when working with AIDS patients." Whalen goes on to note that despite a "specially arranged session with an infectious diseases attending physician," many of the other medicine clerks maintained that they should be "accorded a special status" in regard to working with AIDS patients.

Kelly et al.'s (3) study of 119 second and third year medical students also highlighted the fact that a significant number of the students had "stigmatizing, negative attitudes toward homosexuals." The authors also stated that "their findings were quite alarming" as they did not anticipate the "medical students to such a great extent would believe AIDS patients were more deserving to die, to lose their jobs and to be quarantined."

Bartnof, Mandel et al.'s (4) survey of UCSF medical students published in 1987, revealed that a disquietingly high number of students (29 percent) thougt that hospital employees should have the right to refuse to care for patients with AIDS. In addition, 30 percent expressed a definite preference to avoid caring for AIDS patients.

In response to those studies as well as to others, the Association of American Medical Colleges (5) issued a statement reaffirming that each medical school

and teaching hospital must "accept the responsibility to help medical students, residents, and faculty address and cope with their fears and prejudices in treating HIV infected patients."

The American Medical Association (6) also clearly stated the policy that "physicians may not refuse to care for patients with AIDS because of actual risk or fear of acquiring the disease."

While there has been a definite decrease in the number of students applying to medical school (7), as of today there is no conclusive data to indicate that such a decline is definitely related to the AIDS epidemic. However, there is considerable anecdotal data (8) that indicates "the proportion of medical students choosing residencies in AIDS epicenters has declined and observers have increasingly noted the impact on training programs of the preponderance of HIV related cases in these centers."

There is also speculation that AIDS is somewhat responsible for the increase in the number of students choosing high technology specialities (radiology, ophthalmology, anesthesiology). "It is feared that AIDS itself is dissuading medical students from entering internal medicine. The prospect of caring for so many young patients with fatal disease, expressed or unexpressed homophobia, cultural biases against poor and minority patients, and anxiety over occupational exposure to HIV may all be playing a role in avoidance of internal medicine." (9)

EDUCATIONAL OBJECTIVES AND FORMAT FOR AIDS CURRICULUM

At Northwestern University, medical student education emphasizes approaching the patient from a biopsychosocial frame of reference. Simply stated, "The goal is to provide the student with an understanding of the illness that is based on and derived from an appreciation of pathophysiology of disease as it interacts with psychological and social factors." (10)

Based on our experience and that of other educators, it is evident that the students' receptiveness to absorption and comprehension of the magnitude of the social, psychological, and medical aspects of such a complex syndrome can best be achieved when the curriculum format allows for: (a) didactic transmission of information (through lectures and assigned readings); (b) processing of the information (through small group discussion); (c) supervised clinical experiences during the clerkship rotation.

As educators we recognize that teaching strategy and format must be intricately linked to the objectives described above.

Component (a), "the didactic transmission of information," must be integrated within other medical school courses such as: introduction to the patient, physical diagnosis, behavioral sciences, infectious diseases, etc. Included in

that category are topics such as the symptoms and signs of ARC and AIDS, including the neuropsychiatric symptoms, present prevalence data, transmission and prevention strategies (safe sex, avoidance of sharing of needles, high risk behaviors and the social milieus in which they occur), ethical and legal issues related to testing (the right to privacy, the limits of confidentiality), laws relating to AIDS regarding competency, decisions about artificial life support and resuscitation, and accurate medical information concerning conventional as well as experimental treatment options.

Component (b), "processing of the information." Although Ostrow (11) correctly points out that medical students might benefit from more "information," Goldman (12) emphasizes the need for helping medical students "deal with the strong emotions associated with the deadliness of the disease, with the fact that most patients are homosexual men and intravenous drug users."

Indeed, from the very beginning of the epidemic of AIDS, compassion toward the person with AIDS (PWA) has been an issue. Friedland (13) discusses in depth what he sees as the possible roots for this lack of compassion toward the PWAs. He identifies (1) "a continuing fear of transmission: a deep visceral conviction that a virus...that causes such a devastating...illness must be easy to acquire; this belief carries with it an unrealistic insistence that we be absolutely certain of the way this virus cannot be transmitted;" (2) "our views of the social worth of individuals. These views have two components. The first is a disapproval of the behavior and on differences in race, ethnicity, social class, that characterize the present demography of AIDS.... The second component of social work is a belief that most infected individuals have brought their illness upon themselves;" (3) "the nature of plagues in our mind and human history. We still find it hard to believe that we are in the midst of an unprecedented catastrophe, we feel powerless...vulnerable and frightened. Thus the victims of this plague remind us of our fragile mortality and we shun them for this unwelcome message."

Our experience has shown that "while the students learn easily the scientific data regarding AIDS, the psychosocial issues are much more difficult to absorb. Students use denial as a way of not dealing with the difficulties; it is not easy for our students to hear the devastating figures projected by epidemiologists; that the patients who are dying are practically of the same age as themselves; or to know that we all are part of the profession which has not yet found a cure, or a vaccine; or to ask of our students to examine their own sexual behaviors, values and attitudes." (14)

These issues should be approached through regularly scheduled student-faculty discussion groups spread throughout the 4 years of medical school. These groups provide opportunities for students and faculty to discuss their concerns about working with AIDS patients. The concerns usually span the spectrum from feelings of avoidance and aversion to a reassessment of one's own values. It is in these groups that the interplay of the medical, social, interpersonal, and psychological factors begin to emerge. Depending on the course of the illness, the various themes may have a different focus. For

example, at the time of the diagnosis the student will need help to understand the patient's feelings of denial, anger, guilt, self-blame, "others" blame, self-rejection, and rejection of others. During the mid-stage of the illness the patient is more likely to begin experiencing loss of hope. He/she might feel exhausted, physically and emotionally, and may be financially depleted. Deep feelings of grief and depression and thoughts of suicide are not uncommon. During the later stages of the illness the work that needs to be done with the patient is not unlike working with a terminally ill patient. Death and dying issues dominate. Each of these phases will present a series of emotional challenges that the student will need to address.

Component (c), "the clinical approach," involves the acquisition of therapeutic skills that would enable the student to better help and treat the AIDS patients and their families. Here the opportunity is provided for the student to model him/herself after the appropriate attendants who are actively engaged in the treatment of patients with AIDS.

In summary, we think an AIDS curriculum needs to incorporate the three components mentioned above and be spread over the 4 years of medical school with special attention paid to the developmental issues concerning (1) information; (2) attitudes/values; and (3) clinical practice.

References

1. Morgan, M.M., Curran, J.W. Acquired immunodeficiency syndrome: Current and future trends. Public Health Reports, 101:459-465, 1986.

2. Whalen, J.P. Participation of medical students in the care of patients with AIDS. J Med Educ, 62:53-54, 1987.

3. Kelly, J.A., Lawrence, J.S., et al. Medical students' attitudes toward AIDS and homosexual patients. J Med Educ, 62:549-556, 1987.

4. Bartnof, H., Mandel, J., et al. AIDS education in medical nursing students: Knowledge and attitudes correlates. Abstract, III International Conference on AIDS. Washington, D.C., June 2, 1987.

5. Resolution approved and endorsed by the AAMC Executive council, February 25, 1988.

6. Council on Ethical and Judicial Affairs: Ethical issues involved in the growing AIDS crisis. JAMA, 259:1360-1361, 1988.

7. Jonas, H.S., Etzel, S.J. Undergraduate Medical Education. JAMA, Vol. 260 No. 8:1063-1071, 1988.

8. Healton, C. Discussion paper, Associated Medical Schools of New York, Deans' retreat, 1988.

9. Colton, D.G. The impact of AIDS on the medical care system. JAMA, Vol. 260, No.4:519-523, 1988.

10. Frazier, S.H. Challenges in Psychiatric Education in Training Psychiatrists for the 90s'. Nadelson & Robinowitz (Eds.) Washington, D.C.: American Psychiatric Press, 1987.

11. Ostrow, D.G. Medical Response to Acquired Immune deficiency Syndrome. In Psychiatric Implications of Acquired Immune Deficiency Syndrome. Stuart E. Nicholls and David G. Ostrow (Eds.) Washington, D.C.: American Psychiatric Press, 1984.

12. Goldman, J.D. An elective seminar to teach first year students the social and medical aspects of AIDS. J. Med. Educ., 62:557-561, 1987.

13. Friedland, G. AIDS and compassion. JAMA, Vol. 259, No. 19:2898-2899, 1988.

14. Sheridan, K. Medical Leadership in AIDS Education for Health Care Professionals. Symposium proposal for Rime conference/AAMC, Washington, D.C., 1987.

THE EAST CENTRAL AIDS EDUCATION AND TRAINING CENTER FOR HEALTH CARE PROFESSIONALS

Lawrence L. Gabel, The Ohio State University

PURPOSE

The East Central AIDS Education and Training Center (ECAETC) was developed by representatives of Ohio State University, University of Kentucky, University of Michigan, Meharry Medical College, University of Cincinnati, and the Cincinnati Board of Health to meet the intent of the Federal Government to establish AIDS regional education and training centers across the United States. We directed our collective efforts to:

1. represent a multistate region;
2. demonstrate strong collaboration versus competition; and
3. support, and be supported by, a wide range of health and health-related organizations and societies in the development and dissemination of education and training products and processes.

We believe our accomplishments demonstrate that we will be successful in achieving the purpose of the project. This purpose is: to establish and maintain the East Central AIDS Education and Training Center for Health Professionals, (ECAETC), which will be committed to the development and dissemination of information and materials to facilitate rapid and meaningful education and training of health care professionals relevant to prevention and care regarding AIDS.

ORGANIZATION

The Ohio State University is the lead institution for the project; it administers the project through contractual arrangements with the University of Kentucky, University of Michigan, Meharry Medical College, and Cincinnati Board of Health in conjunction with the University of Cincinnati. It is also recognized as the official location of ECAETC. All of the other four entities are recognized as official ECAETC sites within the region. Through this design, the ECAETC has a definitive centrality, is regional in nature, can marshal a maximum of resources, and can achieve its purpose efficiently and effectively.

Two committees are important to the project. These are: (1) the Criteria/Assessment Advisory Committee and (2) the Professional Liaison Committee.

The Criteria/Assessment Advisory Committee represents:

Sexually Transmitted Disease Centers
Substance Abuse Centers

Hospitals
Home Health Care
City Health Departments
State Health Departments
Area Health Education Centers
Alternative Lifestyles
Mental Health Agencies
Minorities
High Incidence Areas

The Criteria/Assessment Advisory Committee serves a number of important roles. These fall mainly into two categories: (1) advising on the overall needs regarding educating and training health care professionals about AIDS and (2) providing formative and summative evaluation as the curricula materials are developed and delivered. The various members also make recommendations regarding the issues or agencies they represent. This includes facilitating contact and involvement with each representative to insure maximum benefit in support for and from the ECAETC.

The Professional Liaison Committee represents:

American Academy of Family Physicians
American Dental Association
American Medical Association
American Nurses Association
American Osteopathic Association
American Society for Allied Health Professions
Association for Clinical Pastoral Education
National AIDS Network
National Association of Community Health Centers
National Association of Social Work
National Hospice Association

The Professional Liaison Committee serves at least three major roles. First, it advises the Project Staff on issues related to the various health care providers' needs and interests regarding AIDS. Second, it facilitates and provides official entree to the State chapters of each association within the four-State region. This includes using the various associations' communication links to announce education and training opportunities in a given State or in the region. Third, the associations' representatives disseminate information about the ECAETC's materials and offerings at a national level. This serves two purposes. One is to apprise the broader membership about what is available regarding information, education, and training opportunities from the ECAETC. The other is to allow each to work with other ETC's to advise the appropriate personnel about the pros and cons of the ECAETC and what they might or might not want to incorporate as efforts are made to develop a given ETC.

GOALS AND OBJECTIVES

In support of the project's purpose, we have five unique but interrelated goals. These were established on the basis of a Center function to include a(n):

- Organizational Function
- Materials Development Function
- Education and Training Function
- Information Collection and Dissemination Function
- Undergraduate and Graduate Curriculum Infusion Function

Based upon the function-oriented goals, the ECAETC programming efforts are focused on specific objectives. These include: (1) education and training for primary health care providers on prevention and treatment of AIDS, with particular emphasis on ambulatory settings; (2) guidance in the development of a multidisciplinary approach to the management of AIDS/HIV infection; (3) provision of additional training to selected individuals to qualify them for extending the training to others in their community; (4) provision of updates of new and timely information about AIDS/HIV to primary and secondary health care providers; and (5) serving as a support system for area health professionals through hotlines, clearinghouses, referral activities, and the development of learning resources.

SUMMARY

In response to issues surrounding Acquired Immunodeficiency Syndrome (AIDS) the Federal Government, along with governments at other levels and various agencies and associations, has moved aggressively. One response at the Federal level has been establishment of 11 regional education and training centers throughout the nation. Each operates independently; however, there is commonalty across all in purpose and intent.

The East Central AIDS Education and Training Center for Health Professionals serves Michigan, Ohio, Kentucky, and Tennessee. It is a collaborative effort between The Ohio State University, University of Kentucky, University of Michigan, Meharry Medical College, and the Cincinnati Board of Health in conjunction with the University of Cincinnati. Fiscal and administrative responsibilities of the ECAETC are discharged at The Ohio State University; site offices exist at the other institutions to better serve the health care professionals in all four States.

Considerable energy and efforts are being expended by the ECAETC personnel to assure breadth and depth regarding input, support, and service. As a result, large expectations have been established for the education and training activities in the region. Because of this, the Federal ETC concept, as represented by the ECAETC, is seen as being very efficacious and, above all, a cost effective means to achieve the established mission and goals.

HEALTH PROFESSIONALS AND AIDS: THE NEED TO KNOW

Nancy Kilpatrick, Office of Program Development, Bureau of Health Professions; June Horner, AIDS Education and Training Section, Bureau of Maternal and Child Health and Resources Development

This presentation gave an overview of the mission of the Health Resources and Services Administration and HIV/AIDS, with particular emphasis on programs and related efforts to promote relevant preparation and education of health professionals.

The Health Resources and Services Administration (HRSA) is one of seven agencies of the Public Health Service. Its dual mission is: (1) to provide services to populations with special needs and (2) to provide leadership with respect to the education and training of the nation's health professionals. Similarly, the HIV/AIDS mission of the Agency is two-fold: (1) treatment and care of persons with or at risk of HIV infection, and (2) serving as the lead agency of the Public Health Service for oversight of training and education of health professionals.

For the purposes of this presentation, a variety of ongoing HRSA AIDS activities are discussed. Some are targeted AIDS programs or activities. Others are much broader, but focused through an AIDS service and health professional education lens. The HRSA mission was divided into five major areas for discussion purposes.

(1) In terms of addressing the health care needs of special populations, HRSA administers 550 community and migrant health centers across the nation. About 60 percent of these involve rural sites and the majority of care provided in all the centers is maternal and child health. However, health care professionals within some of these centers have been provided with AIDS training materials and protocols on counseling and treatment. Related efforts will continue in the coming year.

(2) HRSA is encouraging community coalitions to plan and organize AIDS health care delivery through three major grant programs. First, a network of 13 AIDS service demonstration projects has been established in metropolitan areas experiencing the highest incidence of AIDS. (Note: Subsequent to the conference, 8 awards were made for a total of 21 service demonstration projects.) These projects support the organization of coordinated systems of continuous, comprehensive care that is also cost effective. These services are aimed in part at high-risk ethnic minority populations and IV drug users. A second program of pediatric AIDS health care demonstration projects is about to get underway. The projects will demonstrate strategies and innovative models for intervention in pediatric AIDS and coordination of services for children and women of child-bearing age who are HIV-infected or at risk. Third,

HRSA has launched a program for the renovation or construction of non-acute intermediate and long-term care facilities for patients with AIDS. Nineteen grants have been awarded (since the Charleston conference) to assist hospitals and other public and nonprofit private entities.

(3) HRSA supports the development and/or improvement of health professional capabilities through support for training and education. Vis-a-vis HIV/AIDS, the centerpiece of the HRSA training effort is a program of education and training centers (ETCs). Now numbering 13 (an increase of two since the Charleston conference), these centers are regional training resources for health care personnel who are providing care to persons with AIDS and other HIV related conditions. Training emphasis is placed on preparing community primary care providers to counsel, diagnose, and manage patients and their families. In addition, selected trainees are prepared to serve as instructors in their local areas.

In addition to this major grant program initiative, HRSA has taken several other training approaches to focus attention on the need for preparation of the health care workforce to prevent AIDS and to care for persons already infected with the HIV. For example, "funding priorities" have been used to allow some preference in the order of funding of approved project applications under primary care training grant authorities, such as Physician Assistant Training and Advanced Nurse Education. This provides a modest incentive for applicant health professional training programs or schools to give special attention to AIDS educational issues. Some contract monies have also been expended for development of AIDS-related training. In particular, HRSA has funded HIV/AIDS curriculum development for public health personnel and for administrators of health care facilities. In both instances, a two-week training package is to be developed, pilot-tested, and disseminated. A "train-the trainer" approach will be used in order to more efficiently employ limited resources. Both efforts are designed to complement the ongoing work of the AIDS Education and Training Centers. (A third contract, awarded September 30, 1988, will evaluate the ETC program.)

In addition, emergency medical technicians (EMTs) were identified at a 1987 HRSA conference as a group in immediate need of training and information. This summer, the Centers for Disease Control entered into a cooperative agreement with the American Red Cross to comprehensively address the needs of EMTs (as well as fireman, law enforcement personnel, and other "professional rescuers" such as lifeguards and security guards). HRSA will assist, as needed, in the development of this effort.

(4) As alluded to above, collaboration with other Federal agencies in providing services and in planning and implementing training is another important aspect of HRSA's AIDS-related activity. Coordination occurs formally through membership on the Public Health Service Executive Task Force and through less formal linkages. An example of the latter was a recent request by the Department of Defense for information on the ETCs as potential nationwide

training resources. Some contacts/connections have been made on local levels as a result of this type of collaboration between Federal agencies.

(5) Lastly, HRSA encourages linkage with public and private sectors for both health care delivery and health professional education. This includes working with State and local governments and professional associations and foundations. An example is a collaborative effort among HRSA, the CDC, the American Association of Dental Schools, and the American Dental Association to develop a comprehensive education program for infection control, including HIV/AIDS prevention. Another example is the emergency fund which awarded monies in FY 1988 (and continuing into FY 1989), by formula, to States and Territories to reimburse for AZT. The monies are intended to pay for life-prolonging drugs for low-income AIDS patients not covered by Medicaid or private insurance.

In conclusion, HRSA is working on several fronts to address the educational needs of health professionals concerning the subject of HIV/AIDS. As you are aware, two recent reports, the Institute of Medicine's update of Confronting AIDS and the report of the Presidential Commission on the HIV Epidemic, are replete with educational implications and specific recommendations relative to the education and training of professionals. HRSA, as the lead agency in this area within the Public Health Service, is making progress. Additional needs are apparent. During FY 1988, which begins on October 1, 1988, HRSA will continue its efforts with some streamlining of activity. There are some new service and education initiatives proposed in the President's 1990 budget but many changes are expected before these are acted upon. A new President and a new Congress will make these future decisions.

PREPARING COMMUNITY DENTISTS TO PROVIDE CARE TO HIV-POSITIVE PATIENTS: AN EDUCATIONAL NEEDS ASSESSMENT

Bryan Maguire, and Barbara Gerbert, Center for AIDS Prevention Studies and Oral AIDS Center, Department of Dental Public Health and Hygiene, University of California, San Francisco

(This research was supported in part by a grant from the American Fund for Dental Health and a Center grant #MH42k459 from the National Institute of Mental Health and the National Institute of Drug Abuse.)

Dentists are called upon to accept several responsibilities in response to the HIV epidemic (1). First, they must continue to provide their services in a professional manner to all who seek dental care, including those with HIV disease. Second, they must ensure that all patients and dental staff are fully protected from infection. Third, dentists can help prevent the spread of AIDS by detecting early signs of HIV infection that appear in the oral cavity or on the head and neck so that patients can be identified and treated in a timely manner.

Reports in the media indicate that dentists are not meeting these responsibilities. In fact, dentistry has been publicly chastised for its poor response to the HIV epidemic. Surgeon General C. Everett Koop has criticized dentists and other health professionals for acting fearfully and refusing to treat people with AIDS (2). Newspaper accounts have pointed out that many dentists are resistant to treating people with AIDS; one article reported that only three dentists in Chicago will treat people with the disease (3).

In an attempt to remedy these problems, organized dentistry has turned to traditional educational approaches such as continuing education courses, lectures, brochures, and pamphlets. Yet dentists do not seem ready to render services to patients with AIDS. A recent survey of dentists in California showed, for example, that 74 percent would rather refer AIDS patients or those more at risk to their colleagues(4). One must conclude that dentists in California are not being affected sufficiently by the educational efforts directed to them.

It has been suggested that dentists in California, with its high prevalence of AIDS, might have different needs from those of other dentists in lower prevalence areas. The present study examines the educational needs of dentists from areas throughout the United States.

METHODS

We invited a random sample of 2500 dentists to participate in a nationwide educational trial. One hundred and seventy-two joined the project and completed a pre-intervention mailed questionnaire designed to assess their knowledge, attitudes, and behaviors regarding AIDS and HIV infection. The

questionnaire was based on instruments used for our surveys in California and consisted of six parts.

Part 1 consisted of 12 attitude items with a seven-point Likert-type response format. Eleven of these items were used to create a scale for "willingness to provide access" (to HIV infected patients). Part 2 asked respondents to estimate their chances of being infected with HIV from participating in ten activities ranging from day-to-day interaction with a co-worker who has AIDS to sticking oneself with a needle that has been used on a person with AIDS. Response format was a seven-point Likert-type scale. There were two subscales: risk of casual transmission and risk of transmission associated with body fluids. Part 3 consisted of 14 multiple-choice questions about epidemiology, clinical manifestations, and transmission of HIV. Part 4 gave written descriptions of eight HIV-associated oral lesions and asked respondents to pair them with the name of the lesion. Part 5 asked subjects about their experience treating patients with HIV disease and associated oral lesions, and asked them to report on their practices regarding oral soft-tissue examination. Part 6 consisted of eight questions regarding steps taken to prevent the spread of infection in the dental office.

RESULTS

The subjects were demographically representative of the U.S. dentist population, with a mean age of 42.3 years; 90.6 percent were male and 83.7 percent were general dentists; 16.3 percent were from the nine SMSAs with the highest prevalence rates of AIDS (5) (compared with 13.7 percent of the general population). Tables I through IV show the survey results.

CONCLUSIONS

Dentists' scores on our outcomes in this study did not differ markedly from California dentists' scores in earlier surveys. Thus, their educational needs are similar; they need behaviorally-oriented instruction in infection control procedures, especially accident prevention, and in oral soft-tissue examination. They also need help in coping with the fear that AIDS evokes in themselves, in their staff, and in their patients.

Most continuing education efforts about AIDS and infection control target changes in knowledge. Our findings indicate that knowledge alone did not relate to willingness to treat people at risk for AIDS and those with HIV infection, nor was knowledge related to patient screening behaviors or use of adequate infection control. We believe, therefore, that for dentists to provide safe and effective care during the AIDS crisis, they are more in need of attitudinal change than technical information about patient care.

TABLE I

Comparison of Mean Scores of Respondents in High and Low AIDS Prevalence Areas*

	Areas with high AIDS prevalence n=29	Areas with low AIDS prevalence n=143
Knowledge of HIV disease (Range 0-14)	8.8	7.9
Knowledge of HIV associated lesions (Range 0-8)	4.9	4.0
Willingness to care for HIV+ patients (Range 11-77)	44.2	41.4
Perceived risk from casual contact (Range 1-7)	2.5	2.9
Perceived risk from body fluid contact (Range 1-7)	5.0	5.5

TABLE II

Percent Identifying HIV-Associated Oral Lesions Correctly

HIV-associated gingivitis	78.5%
Early Kaposi's sarcoma	59.9%
Candidiasis	52.3%
Advanced Kaposi's sarcoma	52.3%
Heavy hairy leukoplakia	51.7%
Light hairy leukoplakia	43.6%
Lichen planus	40.1%
Mucosal and gingival warts	34.4%

* No differences significant at p=.05

TABLE III

Percent of Dentists Performing Oral Soft Tissue Examination Procedures

	Never or Seldom	Sometimes, Half the Time or Usually	Always or Almost Always
Extending the tongue to inspect each aspect for lesions.	5.8%	35.5%	58.7%
Distinct examinations of soft tissues	5.2%	29.7%	65.1%
Asking the patient if they have noticed any sores or lesions in the mouth.	21.5%	45.9%	32.6%
Separate note in chart about patient's soft tissue.	20.4%	38.4%	41.2%

TABLE IV

Percent of Dentists (N=172) Performing Recommended Infection Control Procedures

	Never or Seldom	Sometimes, Half the Time or Usually	Always or Almost Always
I autoclave, chemoclave, or dry heat sterilize hand instruments which touch soft tissue.	62.5%	23.8%	13.7%
I autoclave, chemoclave, or dry heat sterilize handpieces and attachments.	4.7%	10.5%	84.8%
I wear surgical type masks, covering nose and mouth.	14.5%	18.0%	67.5%
I wear eye-protection.	4.1%	8.2%	87.8%
I wear a new pair of gloves for each patient contact.	9.9%	20.3%	69.8%
I disinfect chairs after each patient.	22.1%	37.2%	40.7%
I dispose of each needle immediately after use by placing it in a needleproof box.	33.5%	5.4%	61.1%
Additional instruments obtained in an aseptic manner.	9.9%	38.4%	51.7%

References

1. Gerbert, B. Dentistry and AIDS: An Educational Challenge. In Robertson, P.B. and Greenspan, J.S., editors. Perspectives on Oral Manifestations of AIDS: Diagnosis and Management of HIV-Associated Infections. Littleton, Massachusetts, PSG Publishing Company, Inc., 1988.

2. Boffey, P.M. Doctors who shun AIDS patients are assailed by surgeon general. New York Times, September 10, 1987.

3. Smith, D.C. AIDS and the Chicago dentists shines national spotlight on CDS. CDS Review: 14-16, 1987.

4. Gerbert, B. AIDS and infection control in dental practice: Dentists' knowledge, attitudes, and behaviors. JADA 114:311-314, 1987.

5. San Francisco, New York, Jersey City, Miami, Newark, Fort Lauderdale, Houston, Los Angeles, Washington D.C.

AIDS EDUCATION FOR HEALTH CARE PROFESSIONALS

Erline P. McGriff and Patricia M. Hurley
New York University AIDS Regional Education and Training Center
(BRT 000017-01-3)

The goal of the New York University AIDS Regional Education and Training Center is to provide Acquired Immunodeficiency Syndrome (AIDS) education for a variety of health care professionals in a multistate region. The region for the NYU ETC was defined in the 01 year as New York, New Jersey, Connecticut, Puerto Rico, and the Virgin Islands. In accordance with direction from the Office of Special Projects, Health Resources and Services Administration, the geographical region for the NYU ETC has been redefined to include New York City, Suffolk and Nassau Counties of Long Island, Puerto Rico, and the Virgin Islands. The State of Connecticut will be included in the New England region in April 1989. This redefinition focuses the NYU ETC on the epi-center of HIV/AIDS in the United States with approximately 25 percent of the nation's cases and allows for the intensification of educational activities in this area of greatest need.

Accomplishments of the NYU ETC during the 01 year are described briefly below:

Programs for Primary Care Givers and Dentists. Two interactive video-conferences were held for primary care givers. One was aired on April 6 and the other on May 18, 1988. The interactive video-conference for dentists was aired on April 27, 1988. Hospital Satellite Network (HSN), with whom we subcontracted for these conferences reported that 715 primary care givers and 412 dentists in our region had been reached. HSN also reported that in their viewership survey a national audience of 16,150 physicians and dentists was reached. (Copies of these tapes are available from the NYU ETC.)

Workshops for Other Health Care Professionals. An Educational Program Committee met over a period of 6 months and developed discipline-specific modules for nurses; social workers; physical, recreational, and occupational therapists; nutritionists; and rehabilitation counselors. In addition, modules were developed on IV Drug Use, Minorities and Interdisciplinary Care Management. Two others are being developed on Community/Home Health Care and Legal and Ethical Issues.

In the first year three workshops were held in New York, two in New Jersey and two in Connecticut as stipulated in the subcontracts with the professional nursing associations. Twelve workshops were co-sponsored with the NYU AIDS Mental Health Project in New York City. The total number of participants was 1,518 throughout the region. Professional disciplines included: nurses; social workers; physical, occupational and recreational therapists; counselors; clergy; and students from a variety of health programs. Work settings

represented were hospitals, community health agencies, hospices and free-standing clinics.

Train the Trainer Institute. A Train the Trainer Institute was held June 5-10, 1988 at New York University. This Institute represented one of the most cost-effective training methods in that 35 trainers from New York, New Jersey, Connecticut, Puerto Rico, and the Virgin Islands attended. These trainers will return to their areas and train 50 peers during the next year for a total of 1,750 health care professionals trained. Individualized clinical experiences were planned and provided at the New York University Medical Center and other facilities in the region. This Institute will be offered again in the second year.

The AIDS WarmLine. This WarmLine is an informational telephone system serving as a resource for immediate information and referral. An AIDS WarmLine Operations Manual has been compiled. After a start-up period, calls are now being received at approximately six to ten daily from health care providers throughout the region who desire assistance and additional information.

Faculty Institute. A Faculty Institute will be planned and offered in the third year for faculty from institutions of higher education in the region that have health professions programs. This Institute will focus on faculty to develop AIDS content for undergraduate and graduate curricula. Enrollment will be unlimited.

Serving the Needs of Minorities. Workshops are held in areas serving large minority populations. Members of minority communities serve as Instructors to teach content specific to minorities as well as other content. A subcontract with the Minority Task Force on AIDS, Inc. is proving to be effective in providing ongoing collaboration and consultation necessary to address issues relating to minorities and AIDS.

The Advisory Council. The Council of Professional and Health Related Organizations (CoPHRO) assists in meeting the training needs of the target audiences throughout the region. Membership on this Council includes representatives from community-based AIDS organizations, medical and health professions schools, medical societies, hospitals, and other health professional organizations. This Council has committed itself to active participation in the ETC by supporting programs, recruiting members of their discipline to attend programs, and advising regarding the selection of faculty qualified to teach in the various offerings.

The Center of Excellence. Plans are underway for the development of a Center of Excellence on HIV and Minorities. The purpose of this Center is to develop comprehensive approaches and strategies for the continuing education of health care professionals so that they will conduct aggressive outreach and education in minority communities on HIV prevention and related issues. Activities will include further development of content on drug use/HIV and cultural similarities and differences; establishing a network of experts for

referrals and a speakers' bureau; and sensitizing health care professionals to the cultural parameters of sexual negotiations.

Evaluation. The Director of Evaluation has been directly involved with the responsibility to evaluate the effectiveness of the ETC in increasing trainee knowledge and improving attitudes of health care professionals toward AIDS patients. He will also include an assessment of the efficiency of the operation of the Center.

OREGON STATE HEALTH DIVISION HIV PROGRAM: TRAIN THE TRAINERS

Paula Radloff, Oregon State Health Division, AIDS Education Program

The Oregon State Health Division HIV Education Program has developed a variety of HIV prevention education programs. Highlights of these programs include assisting county health departments to offer education, counseling, and testing services; working with community based organizations (CBO's) and AIDS minority coalitions to provide educational outreach; collaborating with Oregon schools to provide professional development and training on the newly developed AIDS curriculum for grades 4-12; and implementing a statewide media campaign with print, radio and television spots to provide Oregonians with accurate information about Human Immunodeficiency Virus disease.

The Oregon State Health Division employs six basic strategies for HIV education:

1. Amplify preventive education measures.
2. Interpret literature and transmit facts.
3. Prepare and procure training materials.
4. Serve as a clearing house.
5. Identify responsible representatives to assist in educational efforts for target populations.
6. Present training workshops for technical and non-technical audiences.

Based on this model, the Health Division has developed Train the Trainers to prepare health departments, agencies, non-profit organizations, institutions, and health facilities to use this model for HIV/AIDS education in their setting. The goal of this training is to educate representatives of various communities and agencies to deliver HIV/AIDS prevention education to their clients, employees, or community members. The annual program consists of 3 intensive days of instruction so that all certified educators are provided with accurate information in order to present education that is consistent Statewide.

The specific objectives of the Train the Trainers include:

1. Provide technical information related to HIV disease.
2. Provide social aspects related to the epidemic.

3. Familiarize participants with original scientific articles about HIV and AIDS.

4. Strengthen ties between the Health Division HIV program, the local health departments and private, non-profit organizations.

5. Distribute new resource materials.

6. Allow time for networking and sharing of mutual experiences.

7. Assimilate information into one's own personal style and experiences.

All participants are given a pre-test prior to the conference to assess knowledge base and a post-test to measure the level of learning achieved at the conclusion of instruction. The first sessions cover the technical and social aspects of the disease. Topic examples include AIDS update, background information on other sexually transmitted diseases, research and medical treatments, infection control, counseling, testing and confidentiality, human sexuality, civil rights and discrimination, alternative care for persons with HIV disease, and the function of the community based organization. In addition to these sessions, each training focuses on a specific area such as gay outreach, education in minority communities, or reaching the IV drug user.

The third segment of the workshop addresses the role of the educator. Current strategies on effective communication and instruction are discussed to help the participants assimilate and apply the information presented. Media relations, program development, and evaluation are segments that allow educators to share ideas and develop applicable programs The training offers personal development by providing ideas for stress management and self-care.

All trainings encourage group participation and public speaking. An example of a culminating activity used last year required all participants to prepare a speech for peer review. Each person worked with an assigned partner to evaluate a journal article. On the last day, the pair conducted their presentation. Audience members asked questions and provided constructive criticism and praise. This exercise is recommended for small groups to allow for important interaction. Evaluations indicated that this activity was beneficial to many of the trainees.

Each participant that completes the 3-day course receives a certificate and a notebook containing written information on training topics, journal articles presented and educational resources. Post-conference follow-up continues with a quarterly newsletter sent to all trainers. The newsletter contains information updates and Statewide educational activities. Regional conferences on topics such as counseling and testing are also made available to trainers. Due to this program, trainers learn they can call their health

departments or the Health Division to access slides, statistics, and literature to assist them in their educational efforts. The HIV trainers also provide the Health Division with key contacts and guidance when consulted on issues related to their clients, agency, or organization.

To develop a training model, county health departments, hospitals, coalitions, community based organizations, agencies and schools will be able to assist in pinpointing specific areas to address and potential candidates for training. A committee with professional representation can assist in the formulation of goals and objectives, recruitment of speakers, and securing location sites and funding sources. The committee should also decide how the information will be delivered and what type of modeling or practice in which participants will engage. Action and discussion-oriented sessions provide optimal learning experiences. The Health Division always tries to use local experts to present information. This not only defrays travel costs, but more importantly, it gives the trainees one more local resource contact.

Part of the success of Train the Trainers is that it allows individuals to communicate with others they might not ever meet. It gives the trainee the opportunity to learn about the importance of HIV prevention education integration and how prevention methods are applicable in a variety of programs. Therefore, it is very important to invite a wide range of individuals to participate in a training program. Potential trainees should include representatives from:

Health Departments
State Agencies
Medical Facilities
Non-Profit Service Agencies
Drug and Alcohol Prevention Providers
Community Based Organizations
Related Professional Organizations
Schools and Universities
Related Minority Coalitions

Train the Trainers can be easily modified to meet specific needs. This model enforces two important elements: continued education and communication. The Train the Trainers model has been extremely successful in Oregon in accomplishing the goal of providing its citizens with a network of educators that furnish consistent and accurate information about HIV disease and its prevention.

AIDS IN MEDICAL EDUCATION

Lee Strunin, Arthur Culbert, Stephen Crane,
School of Public Health, Boston University School of Medicine

INTRODUCTION

It is clear that medical students' clinical training will increasingly include instruction on providing care for HIV positive patients. To assess the knowledge, attitudes, and beliefs about AIDS of first year medical students at Boston University School of Medicine we conducted a survey of students in May 1988. a questionnaire was administered to students as part of an "AIDS Day" held during an 8-week course in Socio-Medical Sciences.

The five major objectives of the study were to determine students': (1) knowledge of HIV transmission; (2) attitudes about testing for AIDS and treatment of HIV+ patients; (3) beliefs about their own risks for contracting AIDS as medical students and physicians; (4) the effect the epidemic is having on career choices in medicine; and (5) personal behavior changes because of AIDS. The students were told that the survey was completely anonymous and confidential; that they were not to write their name on the survey; that completion of the survey was voluntary, and would not affect their grade in the course. The survey was administered to 135 students with a 92 percent response rate. Fifty-six percent of the students were male; 76 percent of the students were ages 20-25, and 86 percent were single. Sixty-eight percent were white, 20 percent Asian, 7 percent Black, and 6 percent Hispanic.

RESULTS

Knowledge of transmission. The majority of students were very knowledgeable about casual transmission of HIV. Concerning sexual transmission the majority knew that AIDS is transmitted by vaginal intercourse and by anal intercourse but there was less knowledge concerning oral intercourse and transmission of the virus. Similarly, the students had less knowledge about transmission from other bodily fluids.

Over 80 percent of students said they knew "a great deal" or "some" about high risk behaviors, at-risk groups, and transmission of the virus. Over two-thirds of students knew "nothing" about the legal obligation of physicians to treat patients, the cost to patient and society, and screening associated with HIV testing.

There were significant differences in knowledge by age. Significantly more students aged 31 and over than those in the other age groups said they knew "a great deal" about medical treatment, how to avoid contracting AIDS as a physician and the cost to patients and society.

Testing and Treatment. Concerning testing of physicians for HIV positivity, almost half the students believed that hospitals should be allowed to test physicians or other health professionals, but just under one-quarter believe that hospitals should be required to do such testing. A majority believe that a physician who has a positive AIDS antibody test should be allowed to have direct patient contact, but over half do not believe that a physician with a positive test should be allowed to do surgery. And a majority believe that a hospital should not be allowed to revoke privileges of a physician who has a positive AIDS antibody test.

When asked whether they thought certain population groups should be required by law to have an HIV antibody test, 50 percent or more of students think prostitutes, IV drug users, and foreigners should be tested. Just under 50 percent think people about to get married and pregnant women should be tested. Just over half of the students said they wanted to be tested for HIV infection .

Concerning the treatment of AIDS patients the students were divided with just over two-fifths responding that they should be allowed to refuse and the same percentage responding they should not be allowed to refuse to treat AIDS patients.

Personal risks. Concerning their own worry about the risk of infection with HIV as students or medical practitioners and the risk of infecting family members of significant others, 90 percent were worried about being infected as medical students and nearly two-thirds were worried about infecting a member of their family. Over 95 percent of students were worried about being infected over the course of their careers as physicians, and over 80 percent were concerned they would infect a family member or significant other.

Changes in behavior. Over one-third of students responded that they had changed their own behavior because of AIDS, of which just over 80 percent reported changing their sexual and/or contraceptive behavior. Of those who changed these behaviors just over half were using effective methods of either using condoms or abstaining.

Career choices. One-third of students reported that the AIDS epidemic has influenced the choices they are considering in medicine, and over half responded that the epidemic will affect their final choice of specialty.

DISCUSSION

This study suggests that the AIDS epidemic may be affecting first year medical students' final choice of specialty. Of particular concern is that over two-fifths of students believe they should be allowed to refuse to treat AIDS patients and what this may imply for patient care and the future of certain medical specialties.

As others have noted, even if fear is given as the reason for not wanting to treat the real motivation may be more complex. Aversion to gays or intravenous drug users, the terminal nature of the illness, and the cost of AIDS patient care are likely other reasons (Annas 1988; Zuger 1987). It has been suggested that those who express strong fears of infection and who stigmatize AIDS patients may be more likely to overestimate the level of risk associated with AIDS care behaviors (Bartnof et al. 1988).

The Association of American Medical Colleges has recently stated that "medical students, residents, and faculty members have a fundamental responsibility to provide care to all patients assigned to them, regardless of diagnosis. A failure to accept this responsibility violates a basic tenet of the medical profession - to place the patient's interest and welfare first (589)." Medical schools should do more to ensure that medical students have the knowledge and skill to treat the disease AIDS and to avoid infection of HIV.

References

1. Annas, G. 1988. Not saints but healers: The legal duties of health care professionals in the AIDS Epidemic. American Journal of Public Health: 78(7):844-49.

2. Statement of the American Medical Colleges. 1988. Professional responsibility in treating AIDS patients. Journal of Medical Education, 6(7): 587-573.

3. Zuger, A. 1987. A residency in medical ethics. Hastings Center Report, pp. 16-20.

Mobilizing Community Resources

TRAINING VOLUNTEERS AT VANDERBILT AIDS PROJECT

Ruth A. Sheets and A. Gene Copello, Vanderbilt AIDS Project, Vanderbilt Medical Center, Nashville, Tennessee

Volunteers, interns, and other unpaid staff are the life-blood of most AIDS Service Organizations (ASOs). Such organizations could never afford to pay for the quantity and variety of services that such persons provide. Nor could money buy the hours, energy, and experience so freely offered.

The work of ASOs is similar to that of most social service agencies. Some of the work requires skills unrelated to the specific issues of AIDS and HIV infection while much of it presupposes significant knowledge of HIV infection and its effects on individuals and the community.

Training volunteers, interns, and staff to adequately meet the ASOs needs is crucial. We may debate the quantity, specific content, and structure of training, but not its necessity. Well trained persons make it possible for ASOs to serve effectively.

Developing training programs is an ongoing process. Techniques and style improve with experience and changing needs. The first training sessions offered by Vanderbilt AIDS Project followed a primarily lecture format, trying to build a strong knowledge base. Over time, we have decreased the lecture time, finding other, more interesting ways of conveying the same information. This evolutionary process continues as we come to define ourselves as an organization and as we identify the community needs we can realistically hope to address. This is also shaped by the characteristics and abilities of the volunteers, interns, and others whom we recruit.

Vanderbilt AIDS Project is a university-based community service organization. Our services include community education, counseling and support services, social and behavioral research, and policy development. We serve Middle Tennessee and parts of Southern Kentucky, an area with one large city--Nashville, several large towns, many small towns, and substantial rural areas. The area is politically and religiously rather conservative. Any volunteer recruitment and training program must take into account the demographics of the region and select and prepare people to work effectively within that environment.

Our volunteers came at first almost exclusively from the Vanderbilt University Medical Center: medical and nursing students and hospital staff. This community still contributes many of our volunteers, but the pool has expanded to include high school and undergraduate students, community professionals, and others. As our volunteer pool continues to broaden, the breadth of our services increases. For example, we can now offer unique group experiences for our clients conducted by storytellers, artists, and nutritionists.

Vanderbilt AIDS Project training required commitment of an entire weekend. Training participants and potential volunteers inform us that schedules often make multi-weekend or multi-evening training difficult especially for those coming from outside the Metropolitan Nashville area. We have experimented with the number of contact hours for training and lean heavily toward 20.

Training has two main goals. First, people must have the basic knowledge about HIV infection and techniques for converting that knowledge into effective education and counseling strategies. Second, we hope to facilitate discussion and exchange of ideas among people who are attempting to meet the challenges of HIV.

We in the United States often lose sight of the fact that we are dealing with a global problem. Thus, we begin training with a presentation on the global impact of AIDS. We then look at the medical aspects of HIV infection and AIDS. After placing the disease in its national and local context, an infection control professional discusses its transmission and prevention. An examination of the psychosocial issues follows. The first day ends with a lively presentation on human sexuality and its relationship to the HIV epidemic.

The needs of volunteers in public education and those involved in support services differ. Therefore, the second day's program begins with a separate session for each group. Each session includes a panel discussion, skill building, and role playing. The goal is to increase each participant's comfort, confidence, and competence.

The groups come together for lunch and a discussion of legal issues. A series of workshops, from which participants may select two, fills the afternoon. Some of the workshops we have offered are virology, IV drug culture, AIDS and the humanities, financial assistance for clients, educating youth, gay and lesbian culture, and educating in religious settings. These change depending upon perceived need in the community and availability of presenters.

The group comes together again for a discussion of religious issues and administration of a knowledge-level multiple-choice exam. Political and legislative issues are important to the Project, so we offer a brief lecture on current legislation and trends. The weekend ends with a panel of persons living with ARC or AIDS and the significant others of persons with the disease.This is often the first time participants have seen AIDS first-hand.

VAPs university base provides many advantages including a wealth of human resources. These include, but are not limited to, infectious disease specialists, virologists, nurses, social workers, chaplains, ethicists, and lawyers. In addition, we have close ties with community-based organizations. These groups also contribute resources to training.

We realize that we try to present a lot of material in a short time, so we strive for variety in presentation style, use of media, and active participation. Ideally,

lunches, dinner, and ample breaks are included in the training since a lot of processing by participants takes place at these times. This processing and interaction can help build a sense of excitement and commitment.

The diversity among training participants is exciting. In the most recent training, high school students shared the experience with physicians, and religious lay ministers with university professors. In addition to our own volunteers we invite those from community-based ASOs. Community professionals and business people also attend.

We distribute a substantial packet of articles, education and counseling guidelines, and brochures available through the Project. In the future, we will mail the packets to participants before the training. The small fee we charge helps to cover the cost of the material as well as the meals.

Volunteers who have already completed our training are invited back to attend Sunday's program as an update. It is gratifying to see that a number of our volunteers do return for the program.

We have learned some very important lessons through planning and conducting training. these may prove helpful to others who conduct training for ASOs.

1. Be sure that the size of the group is easily manageable in the available space. More space is better than less.
2. Ask previously trained volunteers to assist with registration, media, set-up, child care, and other tasks.
3. Leadership of the training should be inclusive of race, gender, sexual preference, and HIV positivity. Trainers should model the techniques trainees should use. People will remember what they have see.
4. Offer refreshments at breaks and provide lunch or ask people to brown-bag it. In this society, food is a good catalyst for communication.
5. Have a participatory activity every hour or two. It can be a brief awareness activity, small group discussion, workshop, role play, etc. Relate it directly to the rest of the program.
6. Leave sufficient time for questions, especially the first day. Having their questions answered helps people move to the next topic more easily.
7. Before the training, inform presenters of the specific issues you feel need to be covered. Discuss the format for the presentation. Encourage speakers to avoid reading from manuscript.
8. Don't batter participants with only the negative aspects of AIDS. Positive aspects can help them find and pass on hope.
9. Watch the technicality of the material. Good training is a careful balance which keeps both professionals and high school students interested and involved.
10. Offer some type of certificate or other acknowledgment of completion of the training.

A STREET OUTREACH WORKER CONSORTIUM FOR AIDS EDUCATION

Sylvia Silver, The George Washington University; Billy S. Jones, Whitman Walker Clinic; Aaron Green, Spectrum-Koba, Beck Young; Second Genesis and the D.C. Commission of Public Health Office of AIDS Activities

The District of Columbia is tenth in the United States in cases of AIDS, reporting 1294 cases as of July 27, 1988 (1). Some of the groups of individuals targeted for outreach activities in order to reduce the transmission of HIV include: intravenous drug users, male and female prostitutes, hustlers, transsexuals, and sexual partners of all the forementioned. Outreach workers distribute condoms, bleach, literature, and deliver a short "rap" about HIV/AIDS to this population. A number of individuals involved in outreach to this population in the District of Columbia are themselves recovering drug addicts who now hold either full-time or part-time employment with various organizations., Most outreach organizations require an individual to be drug-free for a certain period of time before employment with that agency would be considered.

In January 1988, approximately 20 individuals representing various outreach agencies in Washington, D.C. joined together to form a consortium of outreach workers whose primary objective is to reduce the transmission of HIV. This group subsequently selected the name "The Washington Area Consortium of Street Outreach Associations (WACSOA)" and developed a Statement of Purpose, which is:

> "To provide a means for exchanging information, ideas, and resources among organizations providing AIDS prevention and education. To this end, a goal of the consortium would be to ensure that the widest range possible of geographic areas and population types are covered by member organizations. The consortium may also function collectively as an advisor on issues related to street outreach when, and only when, there is total consensus among the membership."

Some of the agencies originally represented included: ADASA; ALIANZA; SPECTRUM; SECOND GENESIS; WHITMAN-WALKER CLINIC; RAP, INC.; SALUD, Inc.; and WACADA. The George Washington University, which has a wide range of ongoing HIV education and prevention activities was represented, as was the D.C. Commission of Public Health. Dr. Reed Tuckson, the D.C. Commissioner of Public Health, attended one of the early meetings of the consortium, and stated he was optimistic that WACSOA could act in an advisory capacity to his office, and be one of the arms of the public health efforts in the District of Columbia. Dr. Tuckson has consistently shown support for the consortium through ensuring that Commission personnel attend meetings, and

work with WACSOA agencies to help alleviate difficulties. The Commission offers support for various endeavors undertaken by WACSOA.

Though in existence for only 6 months, WACSOA has made great strides toward working as a group, determined to coordinate, instead of duplicate efforts. For example, various agencies have "cross trained" outreach workers in particular areas of concentration, demonstrating an efficient way of introducing outreach workers to the different populations of individuals to be served.

An attempt is underway to delineate "turf" of each agency so that the greatest number of individuals can be reached by members of the consortium. A questionnaire has been developed to determine, among other things: (1) number of full-time and part-time outreach workers per agency; (2) geographical areas covered by each agency; (3) number of outreach workers per geographical area per time of day; (4) populations served; (5) items distributed by outreach workers, e.g. condoms, bleach, literature; and (6) problems which have been encountered by outreach workers from police, neighbors, IVDAs, prostitutes/hustlers, business, and the media. It is anticipated that the results of this survey will enable agencies to better coordinate activities and manpower.

Agencies which are engaged in research efforts are able to share information about their activities and data through the consortium. In addition, because a greater number of outreach workers are knowledgeable about a particular research effort, perhaps more of the populations served can be included in research efforts. Recently, a suggestion was made by a consortium member that a coordinated "Question of the Week" be asked by consortium members to help gather information. This suggestion is under consideration by the members.

Fund raising considerations are under discussion by the members so that the consortium will have revenue for operating expenses. At present, different agencies support the mailing of minutes and other correspondence. The consortium would also like to be able to offer support to outreach workers that may be visiting D.C. for particular meetings, such as the "National Conference on the Prevention of HIV Infection and AIDS Among Racial and Ethnic Minorities in the United States:, which will be held in Washington, D.C. this summer.

Items which come to the attention of the consortium for group action are handled through majority rule. Certain issues which have been addressed by this consortium include:

- Relationship of outreach workers to the D.C. Police
- Response to requests by the media for coverage of outreach activities
- Production of identifying apron which can be worn by WACSOA members while engaged in outreach activities
- Production of WACSOA identification card

Advantages recognized by the formation of this consortium include:

(1) Monthly meetings allow for the congregation of outreach workers who may not have another opportunity to share and gain information. Outreach workers from a wide geographical area have attended different meetings, allowing for greater dissemination of information. Meetings begin at 2:00 pm one month and then at 6:00 pm the next month in order to accommodate as many outreach workers as possible. The meetings have consistently been well attended.

(2) Each meeting begins with announcements, by members, thought to be of interest to the consortium. Therefore, information is disseminated in a timely fashion to a large number of outreach workers and associations. Also, since discussions concerning various announcements usually take place, strategies and courses of action can often be immediately determined.

(3) Sharing of resources has taken place. This usually occurs through the avenue of discussion of issues at meetings.

(4) The members support each other in issues and activities, where previously only one agency or group of individuals may have been involved.

(5) Problem solving has become a group effort of the consortium members. More suggestions for solutions can occur, and greater efficiency in handling situations has been experienced.

The Washington Area Consortium of Street Outreach Associations is demonstrating an approach to managing AIDS services. The evolution of this consortium was brought about by its members, and its functions are maintained through its membership.

References

1. D.C. Commission of Public Health, July 27, 1988.

A PROGRAM OF THE VANDERBILT AIDS PROJECT DEVELOPING AIDS PROGRAMS IN RURAL TENNESSEE

M.D. Roberts, A.G. Copello; Vanderbilt AIDS Project, Vanderbilt University, Nashville, Tennessee

A consultative program has been initiated to develop an interdisciplinary team whereby rural health care and religious leaders in Tennessee may be trained to become AIDS program coordinators in rural regions. The consultative program includes needs assessing, setting analysis, program development, implementation assistance, technical assistance, and program evaluation.

Currently there are over 550 diagnoses of AIDS in Tennessee. The urban centers for the State (Memphis, Nashville, Knoxville, Chattanooga) are becoming the epicenters of increasing numbers of diagnoses. When comparing psychosocial effects upon attitudes and behaviors concerning AIDS, there is a marked difference between urban and rural perspectives. As the incidence of the disease increases and spreads geographically (currently in Tennessee, one person per day is diagnosed with AIDS and one person per week dies from AIDS), these perspectives may eventually converge into a more uniform outlook concerning the disease and concerning persons with AIDS. Currently, however, this is not the case.

The consultative interdisciplinary team has done training for emergency medical technicians, operators of nursing homes, rural schools, industries, community centers via "town meetings", and rural churches in various counties of Tennessee. The goal of this program is not a modest one. It intends and continues to aim toward the training of health care, industrial, educational, and religious leaders to become a source of accurate information in order to further the cause of prevention, and to dispel irrational fears. This is done through a series of considerations.

Needs Assessing. This entails determining what tools are needed by leaders of different communities to most effectively reach their communities. What needs are to be considered become paramount when customizing education that will attempt to empower others to make informed decisions that will change behaviors and thus decrease HIV infections. To determine which program works best in a particular setting, an analysis must be made that considers demographics, economics, health care, and predominant religious attitudes. These factors are key elements in establishing programs that will help persons to internalize a sense of altruism and a sense of compassion for persons with AIDS. One must access the institutions or structures of authority currently in place. For example, after analyzing the needs in current rural health care, the consultative program identified some primary needs. First, there was the general lack of access to health care, as there were no providers

(physicians, nurse practitioners) and no facilities (hospitals, primary care clinics). Second was the general lack of health care knowledge. This is due to the scarcity of resources related to rational decision-making. (Usually, there was only one small health care agency serving several surrounding counties.) Third, there was a generally high unemployment rate due to the lack of job opportunities (small industrial base). Fourth, there was an increased need for health services in many of the rural areas, as there was a higher proportion of elderly people, primarily with untreated health problems. All of these factors had to be considered when designing effective AIDS programming in rural health care settings.

Setting Analysis. What are the unique features of a particular small town? This analysis must consider the presuppositions, probable skepticisms and suspicions from various groups, leaders and persons who compose a particular community. Although virtually every adult in the United States is aware of AIDS, the quality of this awareness is questionable. There is a substantial number of people who espouse a misinformed, inaccurate body of knowledge concerning AIDS, particularly about how it is contracted. How is this misinformed perspective formulated? One possible explanation, based on observations, is that in many rural settings there is a pervading skepticism toward science in general and toward a disease that is spread in modes contrary to long-established moral norms. This skepticism arises from what some perceive as scientific ambiguity, for science rarely, if ever, uses the language of absolutes. Therefore, every activity is viewed as a possible means of communicating this disease, be it donating blood, working with a fellow employee with AIDS, using public toilets, or being bitten by an insect. This uneasiness is also exacerbated by two general rural "moral" attitudes: xenophobia (fear of the other or outsider) and homophobia (fear of homosexuals). The goal of prevention via education may thus be at odds with the moral values of certain segments of the population. However, the church (whether urban or rural) that is not afraid to embrace humanity, including all of its ambiguities and variations, will be a healing element in the midst of the AIDS epidemic. Because not all rural institutions are willing to embrace outsiders, certain settings must have education done by indigenous individuals (e.g., peers, friends, ministers, and local officials). If this is not done, the attempt to develop an education program in a rural community will become a pejorative attempt at best. The rural churches are important in the endeavor, as they are traditionally centers for moral formation. Thus the church must be seen as a friend in AIDS education, leading to heightened awareness of prevention and of unique issues that AIDS brings to any community.

Program Development. If one is attempting to empower others to make behavior changes, one must help to facilitate choice through accurate, reliable information. Accomplishing this in any setting must transcend mere "knowledge base dumping" and instead emphasize "wisdom building", wisdom that will help others in knowing what to do with the knowledge gained. What format will

provide this element in the education? What medium is best to use (video tape or slides, e.g.)? What will be best internalized by the participants? One must consider these questions, because knowledge that does not help facilitate choice or lead to behavior assessment is an exercise in futility and easily forgotten. Therefore, each program, regardless of setting, just be sensitive to the aforementioned psychosocial dynamics. For example, a program in a rural setting must establish rapport quickly. This is accomplished by building levels of trust via disclosure, discourse concerning values and attitudes, and empathy and persuasion (instead of coercion). Generally, any program should reflect specific data (where? what study? date of study?), encourage a sense of compassion (moral precepts toward suffering, obligations to care), dispel irrational fears (disclosure concerning contagion), and establish a sense of responsibility for this newly learned information.

The spread of the human immunodeficiency virus is just beginning to impart significant ramifications upon the less populated rural areas of Tennessee. In some settings, psychosocial dynamics may result in attitudes that lead to gross discrimination, blatant threats, and even violence. This may affect the entire family of HIV-seropositive individual, as vividly demonstrated in Lake City, Tennessee. Thus an AIDS diagnosis has become a moral diagnosis. The key to combating this harmful perspective is accurate information concerning AIDS, its transmission and prevention. This should be done by trained individuals who are respected by their own communities. This education should also be done in the language and format that will communicate most effectively in each particular setting. This program is achieving just that in many rural settings in Tennessee.

Sharing AIDS Information

WOMEN AND AIDS IN NEW YORK: AN ORGANIZED COMMUNITY RESPONSE

Marilyn Iris Auerbach, Claire Jagemann, Hunter College; Joanne Mantell, Gay Men's Health Crisis

The slow recognition of the problem of AIDS among women has underscored a system which is unresponsive to the needs of women and children. Prevention, medical, and social services for women have lagged behind those offered to men. This has occurred within the larger context of a system marked with inadequacies in service availability and access, limited educational opportunities, unemployment and under-employment, powerlessness, housing inequities, and the feminization of poverty. The AIDS pandemic exacerbates the existing structural dimensions associated with health and social policies and the role of women.

Women lack the organized political and social advocacy network and visible presence of characteristic the gay male community. This lack of community also means that women do not have a set of prevailing community norms that can be tapped to support behavioral change, advocacy for resource development, or networking and organizational development.

As the number of female and child cases of HIV-infection increases, the gender inequality in service delivery will be exacerbated. Not only will there continue to be problems with inadequate prenatal and post-partum care, but also other problems will be emphasized. Programs which provide coordinated community-based care and the hospice/respite environment for HIV infected women and children are nearly non-existent. These services will need to be developed in addition to foster care placements and special outpatient center for children with AIDS.

The AIDS epidemic has also focused on the crisis in the shortage of drug treatment slots for detoxification beds, residential drug-free, methadone maintenance, day care, intensive group therapy, and peer support in New York City. Women have been especially hard hit by the dual diagnosis of AIDS and drug addiction in themselves and family members, which is sometimes intergenerational.

In order to provide AIDS education and services for women and children which are well coordinated, preventive, supportive and culturally sensitive, the following recommendations are presented:

> A network of medical and social service that provide for acute care, post-hospitalization, and community-based programs for persons with HIV infection, families, and significant others need to be developed.

Children and families need early intervention to identify resources within the immediate family, the local community, and government programs. This should include social and medical supports, including housing, home care, and respite care which will help to keep the family intact without the need for foster care.

Cooperative care, respite care, congregate housing, and other long term care services are required to enhance the quality of life of those with HIV spectrum illness and their caregivers and families.

Comprehensive family care centers for families, children, and adolescents should be developed to address diagnosis, treatment, and follow-up services to include but not limited to pre-natal and well baby care, testing, counseling, psychological support services, day care, education, and linkages with home care and hospitals.

The immediate increase in the capacity for inpatient and outpatient drug treatment services to meet immediate access needs.

There must be education for service providers that is culturally sensitive to the special needs of women, drug users, the homeless and other disenfranchised populations. Education must include cognitive and social skills training for all levels of medical and ancillary personnel.

Support groups must also be provided for women in all aspects of the HIV spectrum illness as well as their formal and informal caregivers. Women must be empowered to work as advocates, prevention educators, and peer supporters.

Two organizations in New York have organized to focus attention and resources on the need for integrated educational and direct health services for women. The Women and AIDS Project (WAP) sponsored by the New York State Division of Women began in the summer of 1986. This group of women representing staff and volunteers from State and local government, health care and human services, criminal justice, religious and minority group organizations met to discuss the escalating impact of the AIDS epidemic on women and children.

The main purposes of WAP were to: advocate for women and children; develop policy statements; testify about issues affecting women and children and AIDS; provide professional education and support and a cost effective method of sharing information; affirm and support those working with AIDS. WAP has been successful in meeting many of these goals through current projects. Members of the organization testified at New York State hearings on the need for HIV policies and services for women and children. Ongoing monthly meetings provide continuing professional education through formal presentations as well as networking sessions. In addition, a quarterly newsletter disseminated to 650 women and men provides information on

educational and research projects, conferences, job opportunities and bibliographies.

While the Women and AIDS Project was meeting the needs of the professional, there was a need for a community group to address the needs of all women. In the spring of 1987, the Women and AIDS Resource Network (WARN) was the first not-for-profit organization in New York City which was dedicated to the issues of women and AIDS. Unlike WAP, the membership is comprised of professionals as well as community members who also sit on the board of directors.

WARN identified its main mission as developing culturally sensitive educational programs and materials, advocating for social services and educational programs for women, and developing information and referral services for women and children, their caregivers and service providers. Initial projects of the organization include a community assessment questionnaire which was sent to community-identified medical, social, educational, and counseling groups to help link and record their services, hours, fee-scale, travel directions, and child care availability. This compendium was the basis for the telephone clearinghouse which answers telephone inquiries from New Yorkers as well as nationwide. Staff and volunteers answer calls Monday through Friday, 9:00am - 5:00 pm.

Counseling and education services have been developed for women and men as well as a linkage made between WARN and the underserved prison population in New York. Participation in the national names project quilt and numerous national and international conferences have provided linkages with other organizations to develop lobbying strategies for issues and services which affect women, their partners and their children.

The issues facing women as the AIDS pandemic continues will need innovative and coordinated approaches to education and direct services delivery. The Women and AIDS Project and the Women and AIDS Resource Networks are two organizational responses to this crisis which can serve as models and resources to other programs with similar goals.

NATIONAL AIDS INFORMATION CLEARINGHOUSE

Ruthann Bates, National AIDS Information Clearinghouse, Rockville, Maryland

The National AIDS Information Clearinghouse was established in October of last year by the Centers for Disease Control, or CDC. We are one of the three major components of CDC's National AIDS Information and Education Program. One is the public information program being conducted through public service advertisements and the national mailing of "Understanding AIDS." The other arm of the total program is the National AIDS Hotline.

Our services are aimed primarily at public health managers and officials, at both the State and local levels, and health care providers. Our secondary audience is the public at large, including AIDS victims.

Our overall mission is to make current AIDS information accessible. By accessible, I mean acquire, organize, review, update, and make available, in whatever form necessary, all types of AIDS information. To make accessible does not mean to duplicate. The clearinghouse is designed to know what is available, and how to get to it. As an example of what we are not designed for is we are not going to provide any bibliographic information on biomedical literature.

We can be described as the Federal Government's principal reference, referral, technical assistance, and publication distribution service on AIDS, one that is available to all of you. The heart of what we are is summed up in three areas: Reference and Referral Service, Publications Distribution Center, and Technical Assistance Unit.

Our specialists in Reference and Referral call upon two enormous databases, the Resource Database and the Educational Material Database. Both are the largest and most comprehensive of their kind anywhere. The Resource Database now contains information on more than 4,000 programs, projects, and organizations providing AIDS-related services.

The Educational Materials Database contains information about specialized education materials tailored to specific audiences, and focusing on different aspects of AIDS. If you're organizing an information program, we can help you locate materials appropriate to your audience.

Not only do we have categorized information about more than 1,000 informational items, we have samples of many of them. They range from study guides to comic books, and they include displays, audiocassettes, videotapes, and computer software.

With the exception of bulk publications orders, your calls to the clearinghouse are toll calls, since the resources are already available to the public toll-free through the Hotline. Not inviting a deluge of toll-free calls to the clearinghouse also allows our reference specialists to concentrate on responding to the needs of you and other priority users.

Our second major element is the Publications Distribution Center. Requests for government publications received by the Hotline are routed to us, as are requests to the Public Health Service and the Centers for Disease Control, Surgeon General Koop is even starting to refer many of his requests to us.

We now manage about 30 titles, including Public Health Service and Red Cross publications, and the Mortality and Morbidity Weekly Report. By the end of our first 9 months of operation, just 2 or 3 weeks ago, we had received nearly a quarter of a million bulk and single-copy requests, and shipped over 32 million copies of publications.

As an extension of our publications center, we also fill the follow-up mailing needs of "Understanding AIDS," providing additional copies where needed, including the Spanish version. Although we weren't designated by name, it was also our return address that was listed on the piece.

Consequently, we get to answer the return mail. As you probably remember, the piece didn't contain a mail response request. But that didn't stop nearly 6,700 people from dropping us a note.

Our third service area is in Technical Assistance. As a part of this service, we provide technical assistance to States or organizations attempting to develop their own clearinghouses or databases, and we provide consulting services for States designing programs aimed at minority populations.

Also available is an electronic bulletin board which makes a direct link with the Hotline, and which connects both of our operations with you -- health and government officials. We also offer on-line access to our databases. This is available to key users on the Combined Health Information Database, accessed through BRS. Free use is given to non-profit organizations and certain government agencies, and we provide training in the access of the databases.

In addition to providing conference support to organizations and agencies such as those which you represent, we are also in the process of preparing a regular newsletter, and we will soon be able to open a public reading room. Other plans include State and regional organizational directories.

Here's how you can ask for our assistance. First, you can call us. Call between the hours of 9:00 a.m. and 8:00 p.m., Eastern Standard Time, at (301) 762-5111 for the Reference and Referral Service. For bulk publications orders, call (800) 458-5231. Or, write to us at: National AIDS Information Clearinghouse, Box 6003, Rockville, Maryland, 20850.

MEDIA USE AMONG GAY MEN IN DALLAS

Marc Lerro, Anne C. Freeman, C.E. Haley, Dallas County Health Department (Dallas, Texas, USA) and J. Tabori, Professional Management Associates (Rockville, Maryland, USA)

INTRODUCTION

The Dallas County Health Department's AIDS Prevention Project focuses on HIV counseling, antibody testing, and community-based education of high-risk individuals in the Dallas area. Gay and bisexual men are a key target for behavior modification efforts. Since 1985, the Health Department has tested more than 6,000 individuals and has conducted knowledge and behavior campaigns through television, radio, print media, and workshops. Self-identified gay/homosexual and bisexual men using Health Department services have repeatedly indicated that they are reached by messages directed through gay community bars, businesses, and publications. However, men who do not frequently use these businesses and services have reported less knowledge of Health Department efforts.

OBJECTIVES

- To identify communication channels among gay men in Dallas in order to target AIDS and health messages.

- To learn which radio, TV, and print media would be most effective at reaching men who may not participate in gay community events where a majority of AIDS education takes place.

METHODS

A 17-question survey (Exhibit 1) was distributed to 200 self-identified gay men, each of whom agreed to give two male friends additional copies of the survey, for a total of 600 possible responses. The anonymous surveys requested information about the television, radio, and print media habits of the individuals. Other sections covered less traditional media channels: libraries, bookstores, motion picture theaters, computer bulletin boards, etc. Each survey included a cover letter and a self-addressed, stamped return envelope to a private post office box. The surveys were bundled in packets of three. The top envelope contained a cover letter that instructed the reader to pass the other two on to "friends who share your lifestyle." The accompanying survey was coded with a small blue dot to indicate the survey was from a first generation subject. In the middle and bottom envelopes were different cover letters requesting survey completion, and surveys coded with a small red dot to indicate a second generation response. Packets were handed to 20 volunteers who agreed to personally deliver them to neighbors, friends, relatives, or co-workers who were gay. The emphasis was on distributing these surveys outside the traditional

channels, such as bars, businesses, and group meetings. The binary nature of the system would reduce bias and speed distribution, moving farther and faster into a group that could be hard to reach.

DISTRIBUTION

The team offered surveys to individuals at the following places: private and public medical facilities, a counseling center, churches, a residential center for AIDS patients, libraries, general public bookstores, private social clubs. Other surveys were passed out to co-workers and neighbors in non-gay identified sites. Volunteers were instructed to offer surveys directly rather than leaving them anonymously for possible subjects. Each volunteer was reminded of the timeliness of the material and the exact number they were agreeing to distribute. Volunteers were encouraged to contact possible subjects who were either openly gay or relatively closeted.

RESULTS

1. As of August 1, 1988, the Health Department had received 137 completed surveys, a 23 percent response rate. Thirty-nine percent were from the first generation group.

2. The average age was 36 years with 41 percent of the respondents being 30-39 years old. Eighty-three percent were Anglo/White and 3 percent were Black, 7 percent were Hispanic/Latino, 1 percent Asian, and 2 percent American Indian.

3. With 22 gay bars listed, 19 percent of respondents reported not having visited even one bar in the previous year. With 28 gay organizations listed, 33 percent of the men who responded indicated not having attended a meeting of any organization. Only 42 percent reported frequently reading a free weekly Statewide gay publication, often cited by gay community activists as a key communication channel, and only 15 percent reported frequently reading the leading national gay news magazine, which is available on a subscription basis. A majority (69 percent) reported having condoms in their homes.

4. When asked an open-ended question about methods of reaching people more effectively, 20 percent recommended television and radio spots and 16 percent recommended direct mail. Seventy-four percent reported having a videocassette recorder/VCR at home and most reported membership in a mass market video club.

CONCLUSIONS

1. The racial mix of respondents was as expected. It was never the intent of this survey to reach a proportional racial mix of gay men in the Dallas area.

2. The 69 percent presence of condoms in the home may reflect either less than desirable condom use, or it may reflect alternative safer sex practices or low risk behaviors.

3. Health educators miss men at high risk of HIV infection by focusing solely on gay community publications and meeting places. Use of gay community periodicals was significantly lower than use of television and radio.

4. Videocassette recorders exist in a majority of respondent homes. TV habits are strongly established. Many men recommended increased use of TV and radio air time.

5. The suggestion of direct mail indicates that people are willing to be identified as gay in order to receive educational information in the privacy of their homes.

1. Sex: Male___ Female___
2. Age _____
3. Home ZIP code _____
4. Race/Ethnicity:
   __ Anglo/White (1)
   __ Black (2)
   __ Hispanic/Latino (3)
   __ Asian (4)
   -- Native American (5)

5. Newspapers & Magazines
   Please check all that apply.

	(1) Often	(2) Sometimes	(3) Never
This Week in Texas (TWT)	_____	_____	_____
Texas Forum	_____	_____	_____
Dallas Observer	_____	_____	_____
New York Native	_____	_____	_____
Advocate	_____	_____	_____
D Magazine	_____	_____	_____
Gay Community News (GCN)	_____	_____	_____
Dallas Downtown News	_____	_____	_____

6. Radio (Please check stations you listen to at least once a week)

a. __KEGL-FM 97.1
b. __KERA-FM 90.1
c. __KESS-AM 1270
d. __KFJZ-AM 870
e. __KKDA-AM 730
f. __KKDA-FM 104.5
g. __KLIF-AM 1190
h. __KLUV-FM 98.7
i. __KMEZ-FM 100.3
J. __KMEZ-AM 1480
k. __KMGC-FM 102.9
l. __KNON-FM 89.3
m. __KPLX-FM 99.5
n. __KQZY-FM 105.3
o. __KRLD-AM 1080
p. __KRQX-AM 570
q. __KOAI-FM 106
r. __KTXQ-FM 102.1
s. __KVIL-FM 103.7
t. __KVIL-AM 1150
u. __KZEW-FM 97.9
v. __WBAP-AM 820
w. __WRR-FM 101.1

7. Television (Please check stations you watch at least once a week)

a. __Ch.4 KDFW-TV
b. __Ch.5 KXAS-TV
c. __Ch.8 WFAA-TV
d. __Ch.11 KTVT-TV
e. __Ch.13 KERA-TV
f. __Ch.21 KTXA-TV
g. __Ch.27 KDFI-TV
h. __Ch.33 KDAF-TV
i. __Ch.39 KXTX-TV
j. __Ch.58 KDTX-TV
k. __ Cable Television

8. How many times a year do you go to the movies?_____

9. How many times a year do you go to a library? _____

10. How many times a year do you go to a bookstore?_____

11. How many times a year do you go to a computer store?_____

12. How often do you use a computer bulletin board?_____

13. Do you have a VCR/videocassette recorder at home? ___yes ___no

14. Do you usually have condoms (rubbers) in your home? ___yes ___no

15. Groups (Indicate below if you have attended a meeting of one of these groups or if you are now (or have been) a member of these groups. Check all that apply.

		Attended meeting(s)	Member
15.1	Lesbian/Gay Political Coalition (LGPC)	___a	___b
15.2	Dallas Gay Alliance (DGA)	___a	___b
15.3	Lesbian/Gay Democrats of Dallas (LGDD)	___a	___b
15.4	Metroplex Republicans	___a	___b
15.5	Oak Lawn Softball Association	___a	___b
15.6	Series '88 (softball)	___a	___b
15.7	Oak Lawn Tennis Association (OLTA)	___a	___b
15.8	Oak Lawn Bowling Association	___a	___b
15.9	LAMBDA Bowling	___a	___b
15.10	Dallas Outdoors	___a	___b
15.11	Greater Dallas Music Foundation	___a	___b
15.12	Turtle Creek Chorale	___a	___b
15.13	Texas Sidekicks/Cloggers	___a	___b
15.14	Oak Lawn Symphonic Band	___a	___b
15.15	DIFFA	___a	___b
15.16	Dallas Tavern Guild	___a	___b
15.17	AIDS Resource Center	___a	___b
15.18	Oak Lawn Counseling Center	___a	___b
15.19	Razzle Dazzle Dallas	___a	___b
15.20	Metropolitan Community Church (MCC)	___a	___b
15.21	Holy Trinity Catholic Church	___a	___b
15.22	Holy Trinity Community Church	___a	___b
15.23	St. Thomas the Apostle Episcopal Church	___a	___b
15.24	Oak Lawn Methodist Church	___a	___b
15.25	Bethany Presbyterian Church	___a	___b
15.26	Beth el Binah (Gay Jews of Metroplex)	___a	___b
15.27	Affirmation	___a	___b
15.28	Integrity	___a	___b

16. Business/Bars

In the last year which of these Dallas places have you visited? Check all that apply.

a. __Club Clearview
b. __SPARX Club
c. __Video Bar
d. __Arena
e. __Buddies
f. __J.R.'s Bar & Grill
g. __Round-Up Saloon
h. __Old Plantation
i. __Big Daddies
j. __651 Club
k. __North Forty
l. __No Name
m. __Eighth Day
n. __Wild Crowd
o. __Party's
p. __Trestle
q. __Hidden Door
r. __T.R. II
s. __Hideaway Club
t. __Crews Inn
u. __Eagle's Nest
v. __Barracks
w. __President's on McKinney
x. __YMCA Park Cities
y. __White Rock Lake
z. __Crossroads Market
aa. __Off the Street
bb. __That Special Blend
cc. __Union Jack Clothing/Hair
dd. __Arresta Cards & Gifts
ee. __Black-Eyed Pea Restaurant
ff. __Omni Video Repair
gg. __Lobo Bookshop
hh. __Fitness Exchange
ii. __La Cage Bookstore
jj. __Club Body Center-Dallas
kk. __Midtown Spa-Dallas
ll. __Paris Adult Bookstore
mm. __Bronx Restaurant
nn. __Lee Park
oo. __Sound Warehouse
pp. __Blockbuster Video
qq. __Tapelenders Video
rr. __Reverchon Park

17. How do you think the health department could get AIDS prevention information to you and your friends?

Thank you for completing this survey.
Please return it immediately to:

Marc Lerro
P. O. Box 64405
Dallas, TX 75206

A MODEL STATE LEGISLATION: THE WASHINGTON STATE AIDS OMNIBUS BILL

P. McInturff, A. Kruzich, Seattle-King County Dept. of Public Health; B. Kelleigh, Northwest AIDS Foundation

The formation of a Governor's AIDS Task Force in Washington State in early 1987 marked the beginning of the development of a Statewide AIDS policy and strategy. Following some halting progress in the initial months, the Task Force "took off" in the late summer and fall and in the process gained considerable interest of key State legislators and their staffs. The Task Force report, issued in late 1987, formed the basis for the AIDS Omnibus legislation which was written for introduction in the upcoming legislative session.

As 1987 came to a close and activity was quickening toward the opening of the legislative session in January 1988, it was becoming evident that (1) AIDS might become the main issue of the session and (2) broad bipartisan support was coalescing for a piece of progressive, far-reaching legislation which would cover education and prevention, health care and social service development, and civil rights issues.

As the legislative session opened, it was remarkable how consensus had built regarding the need for the legislation. A number of seasoned persons working on legislative issues said they could not remember a bill that had garnered such a degree of bipartisan backing.

Even so, a major impediment was placed in the pathway of the bill as it moved forward, and the bill was almost derailed. The issue concerned the prohibition of discrimination of persons with AIDS, AIDS-related complex or persons who are seropositive, whether the conditions are actual or perceived. In the end, the bill was the last one voted out in the session, and this action happened after midnight when the legislative session was scheduled to end.

Interestingly, the opposition was organized by one conservative senator who had not been much of a force on other issues but who was able to miraculously rally a number of colleagues in support of her position with regard to the discrimination issue. Though they lost, her stature has grown enormously, and it is expected that she will be a force to contend with during the next session when it will be necessary to open up the statute to make some minor changes.

With respect to support for the legislation outside of legislators, the local health officers from around the State reached early agreement on the major points in the bill and successfully argued that a public health orientation would be in the best interest for the State's citizenry with respect to AIDS issues. Also, a newly formed coalition called "ASAP", or AIDS Services and Prevention Coalition, with participation form the State hospital association, nurses association, medical association, the Northwest AIDS Foundation, and others focused on

the prevention and service issues in the legislation while the Dorian Group's Privacy Lobby took the leadership for supporting the civil rights sections in the bill.

Funds accompanying the bill amounted to $5.3 million and while this is modest by comparison to amounts allocated by some other States, it was the first commitment in our State of funds to address the AIDS crisis, and in a non-budget year when the Governor had asked for less than $1 million for AIDS, we felt very successful in procuring this amount.

There are three reasons why Washington's legislation is seen as progressive and a model for others. The first is the "Public Health Orientation" of the legislation. The writing of the AIDS Omnibus legislation was grounded on the premise that what is good public health policy is sound AIDS policy. Consequently, the statute contains provisions such as these:

- HIV counseling and testing to be defined by the State Board of Health;
- HIV testing to always be accompanied by pre-and post-counseling;
- Counseling to be available for all pregnant women, persons in drug treatment and persons being treated for sexually transmitted diseases;
- Mandatory testing only of convicted sex offenders, prostitutes, and drug offenders;
- Potential for jail and prison testing with approval of a health officer and documentation of risks to staff; health officer and documentation of risks to staff;
- Testing and counseling sources of accidental exposures to blood by firefighters, health care workers, and the like;
- Voluntary testing and counseling available in jails and correction facilities.

The second reason we believe Washington's Omnibus AIDS bill is an important piece of legislation is the substantial "Civil Rights Protection" it offers. Many of the civil rights protections in the bill emanate from the strong public health orientation with the belief that public health goals cannot be served unless high risk individuals feel free to come forward for testing, counseling, and other necessary services. Key provisions include:

- protection from discrimination under the State's civil rights act for persons with HIV infection or perceived to have HIV infection;
- prohibition of the use of the HIV antibody test for employment screening;
- confidentiality protections for HIV antibody test results with sanctions for breach of confidentiality;
- due process protection for persons believed to be infected and engaging in behaviors which infect others; isolation of individuals

who persist in high risk behavior only after elaborate processes are followed.

The last reason we consider our Omnibus AIDS bill to be a model is its "Sweeping Contents". It carries these provisions:

- Medically accurate AIDS information and education must be offered in the public schools one time a year, beginning with grade five. There is a carefully crafted option whereby parents can, after reviewing the curriculum, opt not to have their children learn about AIDS and associated high risk behavior. Likewise, AIDS information must also be provided in the State's vocational schools and institutions of higher education.

- Professional and State licensing authorities that certify health facilities and providers must adopt rules recommending AIDS training and education for the members of their profession.

- Six Regional AIDS Service Networks will be created across the State. These networks will be responsible for the public health aspects of the legislation and for developing and coordinating a continuum of health and support services for persons with AIDS.

- State statutes dealing with sexually transmitted diseases are substantially rewritten and updated.

- A State Office on AIDS will be created to provide focus and coordination for new activities developed as a result of the legislation.

We are now in the throes of implementing the legislation and beginning to discuss the amount of funding we will seek during the next legislative session. There are many challenges ahead, but the direction provided by the Omnibus legislation points us in the right direction.

Health System Response to PWA Needs

THOUGHTS FOR HEALTH CARE PROVIDERS RESPONDING TO PWA NEEDS

Steve Beck, National Association of People With AIDS

In responding to PWA needs, the first step is asking. Find out from those who directly experience these needs ... by asking. Asking is, in part, what the National Association of People with AIDS (NAPWA) is about.

NAPWA is a definitively grassroots national organization, structurally comprised by 74 PWA organizations in 41 States, with current membership of over 9000 people - all people with AIDS, ARC, or HIV.

NAPWA's philosophy is self-empowerment, or, perhaps more simply, the regaining of an individual sense of self-reliance.

Organizationally, we have four goals that support NAPWA's philosophy; four goals that help us apply the theory of self-empowerment:

1. Creating a national system of PWA administered, PWA focused programs and organizations, a goal we seek to achieve through our local PWA organizations, like the PWA Coalition of Dallas, which provides more housing - PWAs housing other PWAs - than all the housing providers combined in either Boston or Washington, DC;

2. Integrating PWAs as full contributors to AIDS-related activities, such as the upcoming CDC National Minority Conference on AIDS, in which NAPWA members served on the planning committee, and will serve as presenters;

3. Supporting AIDS related education -- general, targeted, and post-diagnostic -- as shown by NAPWA member participation in the recent national PHS mailing, or by the PWA Coalition-New York's Surviving and Thriving with AIDS: Hints for the Newly Diagnosed, of which some 50,000 copies have been distributed internationally; and

4. Promoting research into the treatment, cure, and prevention of AIDS, efforts PWAs have long been involved in and not only in New York and San Francisco, but through Project Inform in Tulsa and Aliveness Project in Minneapolis, organizations which provide the majority of treatment and therapy information currently read by PWAs.

NAPWA is a national organization representing all PWAs; we are systemically inclusive. Illustratively, NAPWA's board is comprised entirely of diagnosed persons and it is geographically diverse. One-third are people of color and almost one-fifth are women; and all transmission modes, save perinatal, are represented.

The Organization was incorporated in early 1987, but its roots extend to 1983, when at the annual National Lesbian and Gay Health Conference, a handful of PWAs gathered and penned the Denver Principles, named for the conference site.

In 1983, that handful, which included Dan Turner, Mike C Allen, and John Lorenzini - all still surviving and thriving - recommended the following:

> "We recommend that Health Care Professionals:
>
> Get in touch with their feelings (fears, anxieties, hopes) about AIDS, and not simply deal with AIDS intellectually;
>
> Take a thorough personal inventory to identify and examine their own agendas surrounding AIDS; and
>
> Treat people with AIDS as whole persons and address psychosocial issues as well as biophysical ones."

Their stated Principles continue with:

> "People with AIDS have the right:
>
> To quality medical treatment and quality social service provision, without discrimination of any form;
>
> To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities...without jeopardizing their treatment, and to make informed decisions about their lives;
>
> To privacy, to confidentiality of medical records, to human respect; and
>
> To live and die in dignity."

To live with AIDS - fundamentally, the why of where we are and what we do as people living with AIDS. People - not victims, not patients - people, with AIDS.

Let me emphasize a point: In your work with PWAs, you should conscientiously strive to humanize your practice by retaining the humanity of your patients, consumers, customers. To achieve this, you must simultaneously be conscious of communities and careful of stereotypes.

One reality of AIDS is that it does affect a few identifiable or identified communities, disproportionately. The unpopularity, together with the vulnerability, of these communities has permitted stereotype to become stigma, and stigma to become the justification of neglect.

As health care providers, who are stereotypically white heterosexuals with middle class values, be aware that most PWAs self-identify, if at all, as members

of communities other than your own. Yet, take care, for PWAs may not self-identify with the same community you may identify them with.

Gay for example, does not neatly equal white; the majority - just over half - of people of color in the United States who have AIDS are men who have slept with other men.

In fact, gay doesn't always even mean gay; in Maryland, one-third of the homosexual/bisexual men with AIDS..have wives.

And IV doesn't mean Black or Latino: illustratively, a full quarter of NAPWA's board are former IV drug users, but only 4 percent of our board represent people of color who have used IV drugs. Obviously, whites use needles. Yet remember that some of those whites are Mid-western college jocks using IV needles to administer steroids, or suburban high school - or younger - kids who have not "just said no"; or Southern medical professionals with easy access to pharmaceuticals and needles.

Humanize AIDS.

A final point: As individuals, you have a role to play beyond the professional one. First, become educators about general AIDS information, because you can help confront misinformation and resulting hysteria; and second, become politically aware so that you can advocate for yourselves and your capacity to serve and to provide. In other words, practice political risk-reduction. Help politicians and policy makers understand what should and what must be done to address AIDS effectively.

THE HEALTH SYSTEM'S RESPONSE TO PWA NEEDS: EXISTING PROBLEMS AND SUGGESTED IMPROVEMENTS

Don Schmidt, Albuquerque, New Mexico

I've been asked to address you today on my perspective about the health care delivery system response to the needs of People with AIDS (PWAs). I was also asked to make recommendations that might improve health care provider-client relationships.

In preparing for today I kept asking myself, "*What* health care delivery system response to PWA needs?" There is no coordinated health care delivery system response to PWA needs in most places in the country.

The services that are provided are for the most part haphazard, hit and miss, isolated not integrated, not to mention underfunded or not funded at all. But, the lack of coordinated health care delivery systems to meet PWA needs certainly makes providing you with some recommendations that might improve provider-client relationships a pretty basic and simple task.

So, I'm here to talk with you about all this today, and I'm very pleased to be here.

First, I guess I need to tell you a bit about me which will tell you something about my perspective.

I am a person with AIDS. I retired last October after spending the last twelve years working as a health and human services advocate and as a program administrator. Before that I spent 5 years providing front-line client services. I believe in building client centered systems of services that meet the needs and protect the rights of the people being served.

I am a fiscal conservative who strongly believes in coordinated and accountable community-based responses to almost all health and human services problems. When such problems are national in scope, I believe in Federal leadership and resources to assure the development and implementation of community-based responses throughout the land.

From early 1985 until late in 1987 I worked as the first Executive Director of New Mexico AIDS Services. I was involved in designing and implementing that model statewide to provide educational and client services program.

During the late seventies and early eighties I was the Executive Director of Patients' Rights Advocacy Services in San Francisco, addressing rights protection and client empowerment.

Before that I worked as the organizer/advocate who put together Minnesota's community-based pilot project for chronic mental health clients, and I served as the first Executive Director of that program. I'm pleased that that program, Sharing Life in the Community, became and remains a model for serving chronic mental health clients in the community. We built a strong enough systems approach with an aggressive case management component so that our clients were not just dumped from the hospitals into the urban jungle and condemned to the helplessness of homelessness.

Over the years I've also worked on system and services development addressing the needs of runaway kids, ex-inmates, gay and lesbian people, and children in foster care.

From my various experiences I have learned that the design of health service delivery systems and the provision of accountable client-centered services is pretty much the same regardless of the client population being served. No new and exotic methods of serving people with AIDS are needed.

During the past month I served on HRSA's review panel assessing AIDS Service Demonstration Project Applications and I reviewed for the Robert Wood Johnson Foundation 23 of the many proposals that they received regarding the provision of AIDS Prevention and Service Programs. These recent activities have provided me with a pretty good current overview of how health care providers are now responding, and how they are proposing to respond, to the needs of PWAs in various communities throughout the country.

Some of the proposals I reviewed were very good in terms of building service delivery systems and providing centralized access points through case management components in order to respond to PWA needs. But, I'm afraid I must also report that some of the proposals that I reviewed can best be described as "opportunistic infections".

But I'm getting a little ahead of myself here. Before getting into my views on how health care delivery systems can better meet PWA needs, let me tell you a bit about my personal background and about my personal experiences related to AIDS.

I am a 38 year old gay man who has been out of the closet in all areas of my life since 1972. I believe I was the first openly gay mental health worker in Wisconsin, then after moving to Minnesota I was once again the first openly gay mental health worker in that State.

I tested antibody positive to HIV when the test first became available in May of 1985. Four months after that I was diagnosed with ARC on September 13th, 1985. Two years and one month later I was diagnosed with AIDS on October 19th, 1987.

I had two back-to-back bouts with PCP during October and November of 1987. During that time my weight dropped from 165 to 128 pounds and I was very, very sick.

I'm currently doing OK but not great. For treatment I am, among other things, on AZT, Zovirax, Aerosolized Pentamidine, and Halotestin. I deal with neuropathy in my feet and hands. I deal with a lot of anemia and resulting tiredness. My granulocyte count has been dipping down to 600 lately. Ten times that number would be much better. And, I am transfusion-dependent.

Hundreds of my personal friends and acquaintances from throughout the country have died of AIDS. Hundreds more are now sick or HIV positive.

I live with a wonderful lover named Rick and a great old sheep dog named Tycho in Albuquerque, New Mexico. New Mexico, by the way, is not a foreign country. There seems to be a lot of confusion about this. New Mexico is one of the fifty States. It's located south of Colorado, east of Arizona, west of Texas, and north of the country of Mexico. New Mexico is the fifth largest State in the country with a population of about 1.3 million. New Mexico is appropriately referred to as "The Land of Enchantment". You don't even need a passport to come and visit us.

My lover Rick is also sick. We are lucky in having a large and caring support system, including supportive families with whom we are very close. We are also lucky to be living in New Mexico where there is now a reasonably good system of services available for PWAs, including a case management system that provides a centralized access point for obtaining those services.

Given this background, now I will focus my comments on PWA needs and on health care delivery system response to those needs.

As I am sure you know, the specific needs of PWAs vary widely from person to person because of differences in our health problems, ages, support systems, living situations, community of residence, cultural and racial communities, and financial resources. Obviously, babies and children with AIDS have different needs than adults with AIDS. PWAs healthy enough to work have different needs than those who are bedridden. The range of needs presented by groups of PWAs are very broad and the specific needs of each individual with AIDS changes over time.

What PWAs have in common is the need to be able to access a vast array of health care and human services.

In order to have even a shot at being successful in fighting for our lives we need current and reliable information regarding treatment options. We need for you to recognize us as consumers of services. We need to make our own choices about what treatment options to pursue. And, we need for you to remember that it is our lives that are at stake here.

To have a hope of living through this horror we must have accelerated efforts in researching, testing, and releasing new and more effective treatments.

We need better ways of administering AZT, the one federally approved AIDS treatment drug. There has got to be a better way to administer AZT than orally, every four hours, around the clock.

To deal with life-threatening illness we need emotional and practical support services for those of us who are sick and for our families, our lovers, members of our personal support systems, and for our service providers.

We need protections against discrimination in employment, in housing, in insurance provision, in health care provision, in human services provision, and in all aspects of our lives. Such antidiscrimination measures must include timely methods of resolving complaints.

We need for the Social Security System throughout the country to provide timely determinations of eligibility for benefits.

We need immediate access to substance abuse treatment services in all communities throughout the country.

We need culturally sensitive service providers who understand and can relate well to the various communities most impacted by AIDS.

We need legal assistance to provide us with individual and class action advocacy services to assure our access to services, entitlements, and benefits, and to protect our legal and human rights.

In order to live fully for as long as we live, we need to be treated as multifaceted human beings like everybody else. AIDS is a big part of what we deal with in our lives, but it is not the only thing in our lives, and it is not healthy for us or for you to define us solely based on our disease.

Among the most crucial things that we need in every community are home-based nursing care, homemaker services, and out-patient primary care clinics. These services allow us to be at home more of the time and reduce the amount of time we spend in hospitals and the amount of money spent on our care.

As I said in beginning my comments this afternoon, very few areas provide integrated, coordinated, systemic approaches to meeting the needs of PWAs. My primary recommendation to you today is to design and implement such systems. HRSA's AIDS Service Demonstration Projects and the AIDS projects funded by the Robert Wood Johnson Foundation provide you a model framework to use in your design efforts.

I want to briefly make six suggestions regarding process issues in designing and implementing health care delivery systems that respond to PWA needs:

1) Involve PWAs in all levels of planning and providing services. Take a cue from those good physicians who carefully look at and listen to their patients in identifying problems and providing patient-centered treatment. Invite us to be partners in our care, partners in system design, partners in policy development, and partners in service provision. This kind of approach will go a long way toward improving health care provider-client relationships.

2) Perform regular needs assessments and base your services planning, system design, and service delivery on the results of such needs assessments. Demand regular and meticulous accountability from all components of your service delivery system.

3) Work together with all public and private entities with the experience or ability to address portions of the presented problems. Mainstream services where possible and utilize existing funding sources as much as possible. Volunteers who are trained and supervised can provide a vast array of direct services. Community-based organizations are probably your best source for skilled and committed volunteers. And, your community-based AIDS service organization can probably provide the leadership in developing an integrated and coordinated system of AIDS service provision in your community.

4) Provide centralized information and case management services. Provide for a centralized access point to all services through skilled case managers. Keep the case loads of your case managers to 25 or less. Have them coordinate individualized case planning and have them seek out those specialized services that some clients need but which are not offered through your established service delivery system.

5) Maximize available Federal, State, and local resources in funding services for PWAs. If your State has not yet applied to the Federal Government for a Medicaid waiver for services to PWAs it should do so immediately. Remember that AIDS is the stated number one health priority in this country. Try to tap mainstream health dollars from State and local sources. Lobby State and local levels of government for program and services funding. Make sure that PWAs are key members of your lobbying team.

6) Make sure that all providers who are a part of your AIDS service delivery system have and follow AIDS nondiscrimination policies. It is time for all AIDS service providers to start practicing what they preach regarding the issue of AIDS-related employment discrimination.

Finally, to improve health care provider-client relationships, I ask health providers to join with People with AIDS in demanding the Federal Government leadership and resources that are clearly required in order to appropriately respond to this epidemic. We need more C. Everett Koops and fewer William Bennetts providing AIDS leadership. We must have a real Manhatten Project-type approach to this mushrooming bomb called AIDS.

As you all know only too well, leadership from the Reagan Administration on this issue just hasn't been there. When they have tried to lead on this issue, they've usually been going in exactly the wrong direction.

As a result of this lack of leadership and the lack of adequate federal resources, we are sitting here in year seven of this nightmare with more gaps than services, being reactive instead of proactive, and just trying to hang on until the Reagan Administration is sent out to pasture.

I urge you to join with me, and with the great majority of People with AIDS, in sending Ronnie back to California. Let's get ready to support and work with a new Administration in a real war against AIDS.

We all know that it's way past time for the feds to stop doing token AIDS Service Demonstration Projects and get down to the task at hand which is helping communities to establish AIDS Service Delivery Systems throughout the land.

It is also way past time to fill all of those empty positions in the Federal programs responsible for AIDS-related research and treatment development. There is so much to do and we're starting so very late.

Did you ever ask yourself how different the federal response to AIDS would be if all of us with AIDS were Caucasian children? I bet you we'd be a bit further along in finding effective treatments. I am certain that coordinated AIDS health care service delivery systems would by now be well established throughout the country.

By helping us to help ourselves, by including us in all aspects of system planning and service delivery, and by treating us as multifaceted human beings, I guarantee you that you will see great improvements in the relationships between the providers and consumers of AIDS-related services.

In closing, one of the things that I have learned from living with AIDS is that it is not necessarily how long I live that is most important. I keep telling my doctor that the quality of my life is more important to me than the quantity of my life. A real live Health Care System Response to PWA needs would be of great assistance in improving both the quality and quantity of life for all of us with AIDS. I encourage each of you to do your part in making such a response a reality.

A PERSONAL EXPERIENCE OF THE HEALTH SYSTEM RESPONSE TO PWA NEEDS

Andrew M. Ziegler, Public Health Foundation, Washington, D.C.

Thank you for giving me the opportunity to discuss the health system response to PWA needs. I'll be briefly speaking on what I feel are the major issues to consider in dealing with the treatment of people with HIV. Please understand that this is just a brief overview, since each point in this talk could be the subject of a separate conference altogether.

I feel I can speak both from a professional and personal perspective, since I'm the AIDS coordinator for a national public health organization, and I am also HIV positive.

In talks of this nature, I find my medical history has become as much a part of my credentials as where I went to school and what I've done professionally. So, that's where I'll begin.

I was tested in December 1986, when I was 24 years old. The test was a prerequisite for entering the Peace Corps, which was to be the start of a career in International Health. The test was done anonymously at a local alternate testing site, since, in case I was positive, I didn't want official records.

When I found I was positive, I felt shock, fear, and loss. The loss was my perceived health status, potentially my life, but above all else, my dream of entering the Peace Corps and having a career in international health, and working in developing countries.

My experience with the health care system was positive overall; but not without frustrations and difficulties.

As a member of a local HMO, I had always been satisfied with the care and felt I had a good relationship with my MD. I trusted him and trust is the key to patient/provider relationship. The MD hadn't dealt with many HIV patients, if any. He was new to it all, as I was, and it was a growing experience for both of us.

When I told him of my seropositivity, he said he wouldn't put it in my medical records. But when I read my chart one day there it was. Trust was tested and strained. He might have had to record it, but he should have discussed it with me first, and involved me in my own care. This made me suspicious and shook the foundations of trust.

I felt rage and anger at myself and the world in general. I knew from my experience as a dialysis tech working with chronically ill people that health care providers are often an easy target for ill people. I was always conscious of my

emotions and tried not to misdirect my anger and use my MD as a scapegoat. That was often difficult due to my MDs jocular approach. He tried to alleviate my anxiety by downplaying my condition. I understood, and basically appreciated what he was trying to do, but it was wrong for me. I felt frustrated at not being taken seriously. His approach made him seem parental and me childlike which was devastating since pride, independence, self-reliance and autonomy are crucial to my feeling of self-worth and desire for survival.

AIDS carries with it one of the heaviest stigmas in history. Fear, shame, pain and guilt are just a few of the many emotions that AIDS brings up in those afflicted. Fear of rejection by friends, family, society and especially health care providers is another major factor. I didn't want to annoy my MD. I wanted to be the "good patient". I wanted him to like me best, so as he'd always seek to help and protect me. But I started to voice my frustrations with his care, concern, and approach to my treatment.

Ever since I found out I was Positive. I wanted to know my T-cell status. For me, it was not so much a diagnostic tool, but a way to gauge where I was in the disease process - a way to take aggressive approach to combatting disease.

But my MD always talked me out of it. He said it would make me more neurotic, and there was nothing that could be done anyway (which was not true since AZT was available). He consistently resisted my requests and again, I felt frustrated, helpless, voiceless, and powerless.

Seven months later I signed up for an experimental protocol for people who were positive. The screening process involved a T-cell check. The procedure was anonymous supposedly, since I gave my initials and my MDs name as an identifier. I was quite surprised when I received a call on my answering machine 2 days later from the researchers telling me to call immediately. My initial reaction was hope. I fantasized that they were telling me it was all a mistake, I was negative, good-bye and have a nice life!!

Not so. The researchers bluntly told me that my T-cell count was 70, ratio .12. They couldn't help me. They told me to call my doctor. Again, my world fell apart. Now everything was more real, and immediate. This gave me an automatic diagnosis of ARC, and made me eligible for AZT. Therefore, I could have started AZT sooner if I had had a T-cell check earlier.

Again I felt a lot of anger and rage at my MD. I felt he had been careless and passive with me. Did he really care at all? I felt my condition could have been greatly compromised by his unwillingness to screen T-cells. I feel he thought he was doing the right thing to keep me from being too neurotic, but shouldn't that have been my decision? Distrust in my MD was further reinforced when he forgot to order my AZT twice and I didn't receive my first dose until one month after my ARC diagnosis. To me, AZT represented hope: not a cure, but an active approach to my treatment. Each minute without that drug felt like a minute closer to my death.

I have been on AZT since last September and I am doing OK - no major problems. My HMO always covered it with $3.00 copayment. In December, during a routine office visit with the PA, she asked how I was planning to pay for the drug now that the HMO was instituting a $3,000 ceiling on all prescriptions? I hadn't received a special letter, only a form letter from my past employer telling of all insurance policies, as it was open enrollment season. I didn't pay close attention to it, unfortunately. I felt that was blatant discrimination by the HMO designed to drive me out of their service, as well as all people in my situation. The HMO seemed callous. I understood as well as anyone else their need to remain solvent, in this age of rising health care costs and cost containment. But they did not seem particularly interested in the human aspect of their delivery of care: no special letter, no offering of assistance by social services in obtaining financial assistance from other sources to obtain this drug.

Luckily, I had coverage from my current employer. I had been carrying the HMO from my past employer, as I didn't want to lose any benefits. But I saw how easily I could have fallen through the cracks. I had to do it all on my own. There was nobody there who offered assistance. My HMO became my enemy rather than my friend.

I am one of the people they don't want - high utilizers not popular in this age of cost containment. I had no faith that they were operating in my best interest. I was clearly being driven out. Like I said, I understand the need for cost-containment as well as anyone else, but at what cost? The price of a human life? The price of my life in particular?

I'm lucky since I know how to access the system - I know how it operates, I know what my rights are, and where to go for assistance, because I am a part of the system professionally. But it's still never easy.

What about the people who don't have the ability or capacity to access the system due to social, economic, educational, or intellectual barriers? How do they access a hostile system, a system designed to discourage their use and participation? How can we make the whole health care experience a little easier on people with HIV? A good place to begin is with the health care providers themselves.

As I said before, trust is the key to a good patient/provider relationship. You need to feel the provider is working with you and for you, not against you. If there is suspicion or mistrust on either part, everything will be a struggle.

Often, providers haven't dealt with HIV before, so it's a new issue for them. While they're learning about the medical aspects of the disease, they should be learning about the emotional aspects as well. Providers need to recognize that HIV brings up a lot of issues for them. Fear of contagious diseases, homophobia and prejudice against IVDUs or minorities, as well as issues surrounding sex and death, are raised. Providers must be able to examine their own personal feelings and responses to these issues and seek ways of resolving their conflicts in order to effectively treat their patients.

Much of the fear and prejudice against gays and IV drug users are based on myths. Health care providers need to educate themselves, as do all people, to dispel these myths and stereotypes. There is no typical gay, or typical IV drug user. We are all diverse people, as you are, with different needs. There can be no assumptions as to who we are and what we need or want. Providers must listen to patients' needs and concerns on a very individual basis. Providers don't always know what's best for us. We often know more about treatment than the providers: it's our problem and we always have to be one step ahead of the game. And providers need to recognize that they can enter into partnerships with more people than just gay white men: gay white IV drug users, as well as gay and/or IVDUs of color, can also play an active and effective role in the patient/provider relationship.

Overall, many health care providers haven't received adequate education about HIV. There is a need for mandatory education of all health care providers, to ensure adequate training in the diagnosis, prevention and treatment of HIV. All health care providers need to understand the scope of needs of people with HIV. These include medical, social, psychological and financial needs. Providers must know how to involve their patients in a wide range of services including treatment protocols. This might be the role of the case manager, but the provider must at least know where to direct their patients to involve them in the system.

In addition, we need to know that providers will protect our privacy and above all else, our confidentiality. Many of us are very private people, and always have been. We fear for our jobs and our rights, with reason. Currently, as before, we have many enemies. In terms of privacy, I can only tell you what it feels like to go to the HMO and have everybody know I have HIV. It feels rotten when the phlebotomist, in front of eight other patients in the waiting room, asks me how I feel, whether I've gotten any "opportunistic infections" yet, and ends with a long, sad sigh of "God I hope they find a cure for you soon". Very sweet, but a little appalling to have my business laid out like that.

I also think it's very important not to view AIDS and HIV infection as separate components. It is clinically more accurate to describe HIV infection as a continuum of conditions associated with immune dysfunction. This way, we can stop pigeonholing people into separate, distinct categories like people with ARC and AIDS. Many people die from ARC before they're ever diagnosed with AIDS, and many of their needs, such as disability and social security are never met.

In terms of service delivery, it's important to establish a comprehensive and coordinated service delivery system for people with HIV, to reduce both fragmentation of services and cost. The answer may lie with case management, which would help ensure that patients don't get lost in the system and fall through the cracks.

I'd also like to see more attention paid to people who are HIV infected and asymptomatic. We need access to better counseling services, regular follow-up by primary care providers, and information about nutrition and other health behaviors that might reduce the risk of secondary infection and prolong wellness.

Although HIV infection isn't curable at this time, many of its manifestations are treatable. With the development of better drugs and treatment modalities, it is even more crucial for early diagnosis of HIV which would result in better care and treatment, and hopefully prolong people's lives.

In addition, more attention needs to be focused on people of color. The impact of HIV infection on Black and Hispanic communities has been strongly felt. Current estimates suggest that over 40 percent of all persons with symptomatic HIV infection are people of color. It's important not to lump all minorities together. The way in which the Black community deals with issues surrounding HIV is very different from that of the Hispanic community, which is very different from that of the Asian community. Education, prevention, and support services must be sensitive to cultural differences and needs in order to be truly effective.

While I don't have time to go into it in more detail, the issue of special populations with HIV needs to be closely addressed as well. These populations include (aside from gay men) IV drug users, the homeless, the mentally ill, infants and children with AIDS, and women.

Finally, one of the most important issues I'd like to leave you with today is that of empowerment for people with HIV. AIDS is not like other diseases and past epidemics. It strikes primarily the most productive group of society - young adults. The disease is complicated by the fact that it first occurred in already stigmatized groups - gay men and IV drug users - and social response has been confounded by moralistic assignments of blame.

Therefore, we, as people with HIV, need to have a voice in the control and treatment of the disease. Listen to our concerns, our needs, our fears, and desires. You don't always know what's best for us. Dialogue inspires trust. We need to dispel the myths and separate the moral judgments from our treatment.

Involve us in making decisions that will affect our lives - not just gays, who have become quite powerful and vocal, but IV drug users and other individuals as well. We are very different populations, with different concerns and needs, and within these populations are subpopulations.

We need to feel in control of our lives, and there is a great need for self empowerment. Nothing inspires the will to live more than self-control, and nothing kills the spirit more than loss of the same.

See us as individual people, not faceless, voiceless, identity-less people with AIDS. Bring back humanity in the treatment of AIDS. We are not so different from you. In fact, many of us are you, and we're just trying to survive.

CMS LIBRARY
3 8095 00016910 8

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service
Health Resources and Services Administration

The University of South Carolina
School of Public Health